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ABSTRACT

A variety of ethical issues confronting the nursing profession are examined in these proceedings. The following papers are presented: (1) "Ethics: Care & Conflict," by Leah Curtin; (2) "The Interface of Politics and Ethics in Nursing," by Mila Aroskar; (3) "Pluralistic Ethical Decision-Making," by Rita Payton; (4) "Compassion, Technology & the Law: Three Forces Shaping Health Care," by Linda Moskowitz and George T. Lukemeyer; (5) "Nursing Ethics: The Everyday Moral Problems," by Carole Caresio and Stephen Roades; (6) "Exclusion and Confirmation: A Phenomenology of Patients' Experience with Caregivers," by Nancy Drew; (7) "Health Professionals' Obligation to Noncompliant Clients," by Jo A. Brooks; (8) "Ethical Evaluation of Nursing Diagnosis," by Mary Ellen Wurzbach; (9) "Nursing Advocate for Client Autonomy: Resolving a Dilemma," by Karla Lowe-Phelps; (10) "Research Report--Moral Distress in Nursing Practice: Experience and Effect," by Judith M. Wilkinson; (11) "Use of Predictive Factors in Severe Head Injury: Ethical Considerations," by Mariah Snyder; (12) "When the "No Code" Becomes an Early Death Certificate: A Case Study from the Family Perspective," by Jane A. Carlstrom; and (13) "Involuntary Hospitalization in the Residential Facility," by Merry Rumppe. (AYC)

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in Nursing
Sixth Annual Fall Workshop

Dilemmas
Issues
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September 5-6, 1985
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HEALTH CARE ETHICS: DILEMMAS, ISSUES AND CONFLICTS

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We are also grateful to MAIN's Administrative Secretary, Vicki Johnson, who prepared all manuscripts for these Proceedings.

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Leah Curtin is best known for her articulate analyses of nursing issues presented as editorials in the journal she edits, "Nursing Management". As a youth she received many outstanding achievement awards in earth science and paleontology. In 1975 she began to focus on health care ethics. Her book, Nursing Ethics; Theories and Pragmatics, co-authored with M. J. Flaherty was published in 1982 by Robert J. Brady Co., Bowie, MD. Another book for which she was sole author, titled The Mask of Euthanasia was published by Alert Publishing Co., Cincinnati, OH, 1975.

With more than 250 other published articles and presentations on related topics to her credit, she is a nationally recognized lecturer and consultant on nursing ethics. Ms. Curtin received her diploma at Good Samaritan Hospital School of Nursing, Cincinnati, OH and her baccalaureate and master's degree from the University of Cincinnati and the Athanaeum of Ohio. Active in the field of ethics, she founded and served as director of the National Center for Nursing Ethics. She also teaches nursing ethics at the College of Mount St. Joseph, OH. She was elected to the American Academy of Nursing in 1982.

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A former Joseph P. Kennedy Jr. Fellow in medical ethics at Harvard University, she is a member of the American Nurses' Association's Committee on Ethics and the Society for Health and Human Values. She is coauthor with Ann Davis on Ethical Dilemmas and Nursing Practice, now in its second edition published by Appleton-Century-Crofts, 1983.

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With undergraduate and graduate nursing degrees from St. Mary's College, Notre Dame, IN and Indiana University, Bloomington, IN, Dr. Payton received a Doctor of Arts in bioethics education from the University of North Colorado, Greeley, CO.

Dr. Payton's specialization is in the teaching of nursing ethics and she was a major presenter at the First Annual Conference of Strategies for Teaching Ethical Nursing Practice held in San Francisco, CA in 1984. She has served as visiting professor and consultant to schools of nursing, religious groups, and professional nursing associations.

An especially relevant publication written by Dr. Payton is "A Bioethical Program for BSN Student" in Ethics in Nursing Practice and Education published by ANA in 1980; and with W. G. Klingberg she has published a two-hour audiotape titled "Ethical Dilemmas in Operating Room Nursing" for the Association of Operating Room Nurses in 1978.

Like Dr. Aroskar, she is a former Joseph P. Kennedy Jr. Fellow in bioethics. Dr. Payton is active on the ANA National Committee on Ethics and the Hastings Center Institute of Society, Ethics, and the Life Sciences.

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He has held numerous academic and administrative appointments with the Indiana University School of Medicine and the Indiana Health Education Telecommunication System, providing consultation through his several advisory posts. These activities reflect his longstanding interest in the advancement of medical education. Elected a Fellow in the American College of Physicians in 1961, he now serves as Secretary-General of that organization.

LINDA D. MOSCOWITZ, RN, JD, President, Legal Resources for Nursing, Valparaiso, IN

A graduate of Newton-Wellesley Hospital School of Nursing. Ms. Moscowitz received her law degree from New York University in 1967. She is a member of the bar in Indiana Federal District Council and has served as law school instructor and nurse in Connecticut, New York, Indiana, and in an Israeli Kibbutz. She was a member of the Connecticut Nurses' Association's Ethics Committee and a legal consultant for the American Journal of Nursing Company's Educational Services Division.

Ethics: Care and Conflict

Leah Curtin, MS, MA, RN, FAAN
Editor, Nursing Management
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In Phoenix, Arizona, Baby "Doe", an infant born with a severe meningomyelocele, was deprived of food and water - at her parent's request and at the order of her physician - even though she could take food by mouth (The Arizona Republic, 1984).

In Bloomington, Indiana, Baby "Doe", an infant born with Down's Syndrome and a correctable esophageal fistula, was refused corrective surgery and deprived of artificial nurtitional life support by court order (Nursing Management, 1982).

In Houston, Texas, Baby "Doe", an infant born with short bowel syndrome, was started on hyperalimentation three days after his birth. Eleven months later, Baby "Doe", deserted by his parents but thriving on his artificial feedings, was deprived of further nutritional life support (Curtin, 1982).

Situations such as these poignantly illustrate contemporary ethical and legal issues. Although each involves both an infant and nutritional life support, there are significant differences among these cases. In this first instance, normal feeding was withheld because surgical correction of the infant's meningomyelocele offered no reasonable hope of survival. In the second instance, surgery was denied by court order because the infant has Down's Syndrome. In the third instance, hyperalimentation was withdrawn when it became apparent that the infant's inability to digest food was irreversible.

Novelist Pearl Buck once commented, "I fear the power of choice over life and death at human hands. I see no human being whom I could ever trust with such power - not myself nor any other. Human wisdom, human integrity are not great enough...". Nonetheless, nature's errors combined with biomedical advances place such choices in human hands. Fearful or not, "Baby Doe" situations demand decision and action. Capable or not, human beings make those decisions and carry out those actions. Each person and institution stands accountable morally and legally for his, her, or its participation in such decisions and such actions.

Questions raised by nutritional life support of Baby Doe stretch beyond the nursery into oncology wards, nursing homes and the far reaches of the federal government. Among the questions raised by these three "Baby Doe" cases are: Does withdrawal of artificial nutritional life support

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*Taken from Leah Curtin, "Should we feed Baby Doe?", Nursing Management, August 1984. Reprinted with permission of the author and publisher.

support constitute killing? Does imminence of death justify deliberate starvation of a person who could eat normally? Does normal feeding constitute an inhumane prolongation of inevitable death? Does the presence of an uncorrectable deficiency or defect (e.g., Down's Syndrome) justify refusal to correct life threatening physicial defects? Where lifesaving surgery is not possible or has been denied, should artificial nutritional life support measures be instituted or, if already instituted, should they be discontinued? Does artificial nutritional life support constitute an inhumane prolongatiion of inevitable death? Once started, can artificial nutritional life support legitimately be withdrawn when its removal causes death? Does parental permission constitute a *sufficient* as well as a *necessary* rationale for withholding or withdrawing nutritional life support? What legal restraints may be imposed on decisions to withhold or withdraw nutritional life support? Let us consider each of these questions.

Does withdrawal of artificial nutritional life support constitute killing? Complex questions cannot be answered simplistically - and this question is far more complex than it looks. Unfortunately, the withdrawal of artificial nutritional life support often tends to be considered under the general rubric of withdrawal of medical life support measures. This tendency adds to the confusion surrounding the issue because it fails to take into account aspects unique to decisions involving termination of nutritional life support measures.

It is one thing to decide not to resuscitate a terminally ill patient; it is quite another to starve a person to death whether or not he has some hope of survival. Among those aspects unique to (or exacerbated by) questions of continued nutritional life support are:

1. Possible violations of basic subsistence rights protected by both moral and legal sanctions. Subsistence rights are founded in fundamental and universal human needs (Bandman and Bandman, 1978, pp. 322-323). Among such needs is the need for adequate nourishment. In short, while everyone does not need resuscitation or a respirator or an artificial kidney, every human being needs nourishment. The very universality of the need forms a just claim (a right) to have the need filled.

2. While maintaining adequate nutrition is an appropriate part of any medical regimen, adequate nourishment itself is not solely within the medical prerogative. That is, it is not a medical option in the ordinary sense. Although the use of respirators, drugs, defribrillators and the like is initiated and discontinued by medical prescription, nourishment is not.

3. Withholding or withdrawing medical life support measures usually is justified on the basis of futility or humanitarian concern. It is extremely difficult (if not impossible) to argue that feeding is futile or that starvation is a humanitarian undertaking.

Surely, to deprive a person of ordinary sustenance is to kill. Thus, we have a duty to feed. However, as the means of providing sustenance have become more sophisticated, what is included in this duty has become less clear. While few among us would consider bottle feeding an infant or spoon feeding a debilitated adult to be moral options, each is an artificial means of feeding. A premature infant may have too little strength to suck and thus need a special nipple for his bottle. A debilitated adult may need his food mashed. Are such minor adjustments in the feeding process optional? From these, it is a short step to the use of tube feedings for premature infants who have no sucking reflex or for adults too debilitated to swallow. Is tube feeding a medical option or a moral imperative? If digestion is impaired, permanently or temporarily, hyperalimentation is the most effective means of feeding. Is hyperalimentation morally and legally required?

Here, at least, some broad though clear distinctions are possible. When feeding could be accomplished by mouth (e.g., bottle feedings with or without a special nipple, spoon feeding whether or not the food is mashed), to deliberately withhold or withdraw it constitutes killing. Neither the technology nor the financial and human cost is excessive. However, the use of tube feedings, gastrostomies, parenteral and enteral nutrition provide limited options. What constitutes these limits - the scope of morally and legally acceptable decisions, the distinction between killing and allowing to die - is not always clear. Indeed, some argue for elimination of all distinctions between killing and allowing to die. While a strong case can be made for voluntary mercy killing, this case breaks down rapidly in the presence of an incompetent patient (e.g., a newborn) (Grassian, 1981, p. 285).

Imminence of death alone does not justify deliberate starvation of a person who could eat normally. If people have any rights at all, they have a right to life. Even in the face of imminent death. If the right to life means anything to all, it means one has a right not to be killed. According to Rawls (1971, p. 114), a right not to be killed entails a right to receive aid "when one is in serious need or jeopardy when such aid can be rendered without excessive risk or loss of another." Providing normal sustenance to a dying patient imposes no excessive risk or loss to anyone. Whether the caregiver is a registered nurse or a family member, whether the patient is hospitalized or at home, bottle feeding an infant or spoon feeding an adult is not an excessive burden. However, the adequacy of the nutrition may vary depending upon the person's condition, prognosis, and volition (McCormick, 1981, pp. 339-351). A terminal patient may be fed on demand (and then only those foods he particularly desires) (President's Commission, 1983, p. 288), and a dying infant may be fed on demand only enough to keep him comfortable. In the face of inevitable death from some other source (e.g., a birth defect, cancer, etc.), nourishment is used to provide comfort - and any means of feeding that produce more discomfort than comfort can be eliminated. In some cases, the patient can clearly tell us what he wants, in other cases we must rely on our own judgement, in all cases the goal is comfort.

Normal feeding in and of itself does not constitute an inhumane prolongation of inevitable death. Every person must die; some of us sooner than others, some of us with more pain than others, some of us more "naturally" than others. But how a person dies is not without moral significance. Surely, if a living being can feel anything at all, dying of dehydration and starvation must be among the most agonizing ways to die. To attempt to end suffering by inducing death through a painful means (e.g., by starvation and dehydration) is morally repugnant. Although a philosophical case could be made for mercy killing through rapid and painless means (a quick overdose), such a case disintegrates totally when the means are both slow and painful. Moreover, lest there be any misunderstanding, let me hasten to add that direct mercy killing, by deliberate starvation of a person who could eat normally or by deliberate overdose, is illegal.

The presence of an uncorrectable deficiency or defect (e.g. Down's Syndrome) in itself does not justify refusal to correct life threatening physical defects such as esophageal fistula or duodenal atresia. Federal law prohibits discrimination against any person solely by reason of handicap. Consequently, the Department of Health and Human Services (HHS) promulgated the "Baby Doe Regulation" which required the posting of a notice (see Exhibit I) and established a Handicapped Infant Hotline. Judge Gerhard Gesell ruled the Baby Doe regulation invalid because HHS had not followed proper procedures in promulgating it (American Academy of Pediatrics vs. Heckler, 1983). George Annas, in commenting on Judge Gesell's ruling, asserted that "Treatment should be denied to a handicapped infant for only one reason: that the treatment is not in the infant's best interests. Withholding treatment in the interests of others [e.g., parents or society] would be a monumental and unjustified change in the law, and runs contrary to child abuse and neglect statutes" (Annas, 1983, pp. 15-16). The President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research in its report, Deciding to Forego Life-Sustaining Treatment, offers some guidelines for determining an infant's best interests and for handling conflict situations (see Exhibit II). By no means are an infant's best interests always served by surgery. However, when surgical repair is possible for something as basic as normal feeding, the courts (and for once most ethicists agree) generally have mandated surgery. If treatment decisions must be taken to court or are the occasion of disagreement, effective artificial means of providing nutritional life support should be maintained at least until the issue is resolved.

Where life saving surgery is not possible or has been denied, should artificial nutritional life support measures be initiated or, if initiated, should they be discontinued? All common measures should be undertaken to assure comfort and solace for infant and parents. Certainly any infant who could be fed by mouth should be fed on demand. When infants cannot be fed by mouth, it sems appropriate to hydrate the child at least enough to prevent suffering. However, tube feedings, gastrostomies and hyperlimentation usually are not in the infant's best interests and can only prolong the suffering of the parents.

Accurate and timely assessment of the infant's condition, appropriate consultation and rapid and honest review of decisions will expedite appropriate management of the seriously ill newborn. In teaching institutions the need to learn, combined in a particularly potent manner with the technological imperative, often urges aggressive and hasty interventions. Senior physicians have stringent obligations to supervise the practice of their junior colleagues to prevent or mitigate the tragedy of overtreatment and inhumane prolongation of inevitable death. Well-intentioned though ill-concerned attempts to shorten the life of a seriously ill newborn similarly demand immediate intervention from superiors. Sensitive consultation, counsel and supervision are as necessary for young professionals - physicians and nurses - as they are for parents.

Indeed, some artificial nutritional life support measures can constitute an inhumane prolongation of inevitable death in certain circumstances. In situations in which death is inevitable and the conditions of living intolerable (involve extensive technological isolation from human touch, futile, pain and pointless extension of dying), highly sophisticated means of feeding are not in an infant's best interests and may be withheld or withdrawn.

Once started, it is extremely difficult to justify withdrawal of artificial means of nutritional life support when its removal causes death. In situations in which sentient life is a reasonable expectation, nutritional life support measures (including hyperalimentation) generally should be continued unless a rational adult patient refuses them. When permanent unconsciousness can reliably be predicted artificial nutritional life support may be terminated. The President's Commission had this to say: "Most patients with permanent unconsciousness cannot be sustained for long without an array of increasingly artificial feeding interventions - nasogastric tubes, gastrostomy tubes, or intravenous nutrition. Since permanently unconscious patients will never be aware of nutrition, the only benefit to the patient of providing such burdensome interventions is sustaining the body for a remote possibility of recovery. The sensitivities of the family and of care giving professionals ought to determine whether such interventions are made... When all remedial attempts have failed to bring the patient out of chronic coma, but where the patient is able to spontaneously maintain respiration and circulation, it would seem to be a matter between physician and family as to whether or not other, more mundane, care would continue...if the family feels the emotional or financial drain too great and the physicians in attendance indicate no reasonable possibility that the courts, when presented with petitions for appointment of a conservator with power to refuse consent to further treatment of any kind, including I.V. drip...can be expected to grant such requests" (President's Commission, 1983, p. 190).

Parental permission is a necessary but not sufficient precondition for withholding or withdrawing nutritional life support. The President's Commission holds that parents who make decisions which are "clearly against the infant's best interests" be disqualified and that civil courts appoint surrogates (President's Commission, 1983, pp. 6-8). Judge Gesell, in his comments on the Baby Doe regulation, notes that "the effort to preserve an unwanted child may require concurrent attention to procedures from adoption or other placement" (American Academy of Pediatrics vs. Heckler, 1983). The right of parents to direct the future of their children is cherished and legally protected, but it is not absolute. Parental rights do not include a right to abandon or to endanger their children or to let their children die when readily attainable assistance is available (Larsen, 1954, p. 283). In short, physicians, nurses and institutions are not relieved of their moral and legal responsibilities for a seriously ill newborn when parents choose a course of action clearly contrary to an infant's best interests rather, their responsibilities are increased and judicial intervention must be sought.

Comments on the cases

Given these general reflections, it seems that a grave injustice was done in each of the three situations presented at the beginning of this article. Baby "Doe" in Arizona, though untreatable surgically, was subjected to an unnecessarily painful and prolonged death. It seems that Baby "Doe" in Indiana was denied his civil rights under section 504 of the Rehabilitation Act of 1973 if, indeed, he was denied life-saving surgery solely because he had Down's Syndrome. The fact that he died before his case could be appealed to the United State Supreme Court underscores provider responsibility for maintaining nutritional life support while the issue still is litigation. His death under these circumstances also produced unprecedented controversy which yielded the Baby Doe regulation which, in turn, resulted in unwarranted intrusions in several situations. Although a case could be made for withholding hyperalimentation from Baby "Doe" in Texas, its withdrawal from a sentient and "thriving" child was not normally justifiable and may not be legally justifiable. Surely, and particularly in the absence of parents or other surrogates, court intervention should have been sought.

The role of ethics committees

Certainly the Baby Doe situations considered in this article are the exception rather than the rule. Far more likely, are situations such as the "Baby Boy Houle" (Hellegers, 1977) case in which vigorous, unnecessary and even inhumane interventions were undertaken in futile attempts to preserve an irremedially damaged infant.

By and large, courts are not necessarily the best places to make care decisions. As the President's Commission pointed out: "judicial review is costly in terms of time and expense; it can disrupt the care of the patient; it can create unnecessary strain between professionals and surrogate decision-makers; and it exposes private matters to public scrutiny and to the glare of public media" (President's Commission, 1983, p. 159). Occasionally, it may be wiser to request judicial review, but in most instances internal review by an appropriate committee is far more desirable. Institutions are urged to develop "clear, explicit, and publicly available policies regarding how and by whom decisions are to be made for patients who lack adequate decision making capacity" (President's Commission, 1983, pp. 5-6).

Moreover, institutions are urged to exercise their responsibility to protect patients' well-being by establishing ethics committees. The recommended role and functions of such committees can be found in Exhibit III. By and large, it seems most appropriate for such committees initially to concentrate on the development of appropriate policies regarding withholding and withdrawing life support, surrogate decision-making, carido-pulmonary resuscitation, and the like. Such policies, once agreed upon by the committee, would be recommended to administration for adoption. Once the policies are adopted, the ethics committee can serve as a valuable resource for education of staff to ensure that the policies are appropriately promulgated. It is only with the greatest reluctance that I concur with the Commission's recommendation that the ethics committees should serve to review particular case situations. "When ethics committees serve as reviewers, they do not supplant the principal decision-makers... (President's Commission, 1983, p. 164)." Presumably, they can serve in an advisory capacity, and they can ensure that appropriate cases go to court. Nonetheless, the problems of patient and family privacy, diffusion of personal accountability, and professional liability loom large. There is no guarantee that a committee will make a sounder or more humane decision than an individual. Whatever else the ethics committees may be, they should primarily be counselors - not deciders.

The make-up of the committee is also of concern. The President's Commission recommends diverse membership: medicine, nursing, pastoral care, attorneys and a public member at the least (President's Commission, 1983, p. 166). Other disciplines could be represented as members of the ad hoc committees of the committee when policy or practice touches on their areas of expertise. Long experience of committees suggest that a committee that is too large (1) will never reach a decision and (2) will have great difficulty gathering members for a meeting (Friedman, 1981, pp. 20-21).

Humane and compassionate care for patients and for families can no more be guaranteed by a committee than they can by a court. Compassion resides in human beings and is demonstrated in human relationships. Courts and committees can ensure appropriate procedure - and undoubtedly will contain abuses - but, in the end, individual health professionals in their intimate interpersonal contacts with patients and families determine the quality of the caring.

Exhibit I

NOTICE
DEPARTMENT OF HEALTH AND HUMAN SERVICES
Office of Civil Rights

Discriminatory failure to feed and care for handicapped infants in this facility is prohibited by federal law, section 504 of the rehabilitation act of 1973 states that

> "No otherwise qualified handicapped individual shall, solely be reason of handicap be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance."

Any person having knowledge that a handicapped infant is being discriminatorily denied food or customary medical care should immediately contact:

Handicapped Infant Hotline
U.S. Department of Health and Human Services
Washington, D.C. 20201
Phone 800-368-1019 (Available 24 hours a day).TTY Capability

In Washington, D.C. call 863-0100

OR

Your State Child Protective Agency

Federal Law prohibits retaliation or intimidation against any person who provides information about possible violations of the Rehabilitation Act of 1973.

Identity of callers will be held confidential.

Failure to feed and care for infants may also violate the criminal and civil laws of your state.

Exhibit II

TREATMENT OF SERIOUSLY ILL NEWBORNS*

- Parents should be the surrogates for a seriously ill newborn unless they are disqualified by decision-making incapacity, an unresolved disagreement between them, or their choice of a course of action that clearly is against the infant's best interests.

- Therapies expected to be futile...need not be provided; parents, health care professionals and institutions and reimbursement sources, however, should ensure the infant's comfort.

- Within the constraints of equity and availability, infants should receive all therapies that are clearly beneficial to them...The concept of benefit necessarily makes reference to the context of the infant's present and future treatment, taking into account such matters as the level of biomedical knowledge...and the availability of services necessary...[this] underlines the ethical duty of the community to ensure equitable access for all persons to an adequate level of health care.

- Decision-makers should have access to the most accurate and up-to-date information... Physicians should obtain appropriate consultation and referrals. The significance of the diagnoses and the prognoses under each treatment option must be conveyed to the parents (or other surrogates).

- The medical staff, administrators, and trustees of each institution...should take the responsibility for ensuring good decision making practices. Accrediting bodies may want to ensure that institutions have appropriate policies in this area.

- An institution should have clear and explicit policies that require prospective or retrospective review of decisions when life-sustaining treatment for an infant might be foregone or when parents and providers disagree about the correct decision for an infant. Certain categories of clearly futile therapies could be explicitly excluded from review.

- The best interests of an infant should be pursued when those interests are clear.

- The policies should allow the exercise of parental discretion when a child's interests are ambiguous.

- Decisions should be referred to public agencies (including courts) for review when necessary to determine whether parents should be disqualified or decision-makers...

Exhibit II (cont.)

- The legal system has various -- though limited -- roles in ensuring that seriously ill infants receive correct care.

- Civil courts are...the appropriate decision-makers concerning the disqualification of parents...and the designation of surrogates to serve in their stead.

- Special statutes requiring providers to bring such cases to the attention of civil authorities do not seem warranted...nevertheless, educating providers about their responsibilities is important.

- Although criminal statutes should be available to punish serious errors, the ability of criminal law to ensure good decision-making...is limited.

- Governmental agencies that reimburse for health care may insist that institutions have policies and procedures regarding decision-making, but using financial sanctions...to punish an "uncorrect" decision is likely to be ineffective and to lead to excessively detailed regulations...

*Deciding to Forego Life-Sustaining Treatment. Report of the President's Commission for the Study of Problems in Medicine and Biomedical and Behavioral Research. U.S. Government Printing Office, Washington, D.C., 20402, March, 1983, pp. 6-8.

Exhibit III

The procedures that institutions establish to promote effective decision making for incapacitated individuals can serve a number of specific functions.

- They can review the case to confirm the responsible physician's diagnosis and prognosis of a patient's medical condition.
- They can provide a forum for discussing broader social and ethical concerns raised by a particular case; such bodies may also have an educational role, especially by teaching all professional staff how to identify, frame, and resolve ethical problems.
- They can be a means for formulating policy and guidelines regarding such decisions.
- Finally, they can review decisions made by others (such as physicians and surrogates) about the treatment of specific cases.

*Deciding to Forego Life-Sustaining Treatment. Report of the President's Commission for the Study of Problems in Medicine and Biomedical and Behavioral Research. U.S. Government Printing Office, Washington, D.C., 20402, March, 1983, pp. 160-161.

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Interface of Ethics and Politics in Nursing

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Can we "do" ethics effectively in the "real" world without also considering politics? Dealing with ethical concerns in the world of nursing practice and service does require dealing with the political dimension as well. Ethics and politics constantly interface or overlap in nursing practice for the administrator, educator, researcher, or practitioner. Although ethics and politics may seem totally divergent--ethics about doing what is right or good; and politics about corruption and manipulation --this is too simplistic a characterization. There are a multitude of ways that ethics and politics are viewed.

Concepts of Ethics

First, ethics is a discipline subsumed within the broader domain of philosophy. That is, ethics is the systematic study of what our conduct ought to be with regard to ourselves, other human beings, and the environment. It is the justification of what is right or good--the study of what our lives and relationships ought to be--not necessarily what they are. Ethics in nursing constitutes an area of applied ethics. Insights gained from systematic study and reflection are used to achieve more ethically adequate decision-making in practice and policy development. Ethics in nursing also includes consideration of the environments in which care of clients occurs and the integrity of individual practitioners of nursing as well as the collective integrity of the nursing profession. More explicitly, ethical situations in patient/client care and in related policy making are characterized by relationships in which:

1) there are conflicts of needs and interests of individuals or groups where the welfare and interests of these individuals and groups are at stake,

2) consideration of ethical/moral principles such as individual autonomy, avoiding harm, and justice or fairness is required,

3) decisions are required to be reflective and deliberative, and

4) feelings and values of everyone close to the situation are involved, whether the situational contexts occur in intensive care, the board room, or the workplace.

Whenever we talk about applying ethical insights and knowledge in the world of practice, we are immediately confronted with the realities and difficulties of complex health care environments, and their political, social and economic dimensions. Nurses are required to carry on ethical decision making in chaotic and hectic patient care settings most of the time. To be able to carry on a reflective process of decision making, there must be change in the practice environment and not solely a change of the individual nurse's behavior. The institutional ethics committee must provide consultation on ethical questions in complex patient care situations where there are often serious disagreements about treatment. Policy review and development in health care institutions must try to incorporate the ethical dimension as explicitly as possible into the areas of institutional life and relationships where physicians are often viewed as the only decision makers of any consequence. Nurse executives are nowadays being pressed to make decisions about reorganization which may include staff cuts. Nurse educators find themselves having to make decisions about students who are questionably competent in client care. Considering the ethics in such typical situations will clarify the ethical and moral values that are at stake, and what ethical justification can be made for one set of actions or another. But in order to facilitate the decision making which takes explicit account of the ethical dimension, the political and power dimensions must be taken into account.

Concepts of Politics

There are many ideas about what characterizes politics all of which probably include the struggle for power as a pervasive feature. Some may think of politics as a science dealing with regulation and control of persons living in society; politics as the work of government and legislators; or as activities concerned with achieving control, advancement, or some other goal(s) in a non-governmental group such as a patient care unit, a long term care facility policy committee, or administration of a community nursing agency. Politics can also refer to relations between leaders and non-leaders in any social group. Additionally, there are ways of looking at politics which show a direct link or overlap with ethics. Examples are: politics as public or social ethics; as a branch of ethics concerned with the state as a whole rather than the individual person; or as a division of moral philosophy dealing with ethical relations and duties of government or other social organizations. Politics can also be thought of as a total complex of interacting and usually conflicting relations between persons living in society (Webster, 1971). This latter concept of politics returns us to one aspect of ethical situations in which the conflict between individual and group needs and interests makes the overlap of ethics and politics more visible.

In their book, Politics of Nursing, Kalisch and Kalisch (1982, p. 31) assert that "the basic definition of politics is the authoritative allocation of resources", that is the allocation of finite resources which are valued in our society such as money, health, prestige, nursing time and expertise. Society sets up political processes to make decisions about such allocations; that is, in deciding who gets what. In this instance we are focusing on nursing and health care. Minnesota nurses who responded to a nursing ethics survey conducted in 1985 by the Minnesota Nurses Association identified the allocation and rationing of scarce resources as "the most important ethical issue facing nursing today"

(Minnesota Nurses Association, 1985). This is an issue which clearly requires collaborative efforts of many individuals and groups and has both ethical and political dimensions. It cannot be resolved by nurses alone or by any other group or discipline working in isolation.

As our society is confronted more directly with issues such as the allocation and rationing of resources, it becomes clearer that much of the work in bioethics and even in nursing ethics which has focused on the intricacies of individual decision making and rights of individuals is not adequate to the challenges confronting us today. We as a society must make sense out of how we plan to use and allocate our resources, including nursing and health care. Callahan, (1980) Director of the Hastings Center (an organization which has provided much of the leadership in dealing with ethical concerns confronting our society), asserted that:

> The increasing necessity to make social and policy decisions for large groups, indeed, for the whole population in some cases, raises fresh and extra-ordinarily difficult moral problems. It will force biomedical ethics to move into the mainstream of political and social theory, beyond the model of the individual decision maker, and into the thicket of important vested and legitimate private and group interests. The language of "rights" is not likely to be up to that task, unless there is a better language for the rights of an entire group, nor is a focus on the intricacy of individual decision making likely to be of much help.

An important step for nursing is to think through how we are to use the insights gained from the general study of bioethics and the specific study of nursing ethics in order to build from an individual patient-centered ethic (grounded in respect for individual persons) toward an ethic which explicity incorporates the values of community. The interconnectedness of these two ethical domains has largely been neglected in favor of the pursuit of individualism in U.S. society. Balancing the pursuit of individual good with the good of the public in the political arenas of health care requires sensitivity to both ethical and political dimensions in the use of ethical reasoning and moral imagination. We can no longer focus solely on individual concerns and well-being.

Politics, Ethics and Nursing Statements

In the ANA Code for Nurses (1985) and A Social Policy Statement (1980), one can find the same tensions and actual or potential conflicts as seen in concepts of ethical and political situations cited previously as examples in the nursing community. The need to balance the interests of the individual nurse as decision maker into the political domain. My major argument is that both political and ethical dimensions are inherent in relationships at all system levels most obviously in policy development. Items in the Code for Nurses focus on provision of service to the individual patient. This takes into account respect for the dignity and uniqueness of the client, the reporting of unethical, illegal and incompetent practice of anyone in order to safeguard clients and the public, *and* the collaboration of nurses with others to meet the health needs of the public.

When involved in the political process in order to achieve the public's good, nurses, according to the *Social Policy Statement* must have the public good as the overriding concern. This tension is further reflected in the *Code for Nurses* in statements about nurses as interdependent members of the community who may find themselves in situations where they will advocate for the well-being of the community because the life of the community is at stake. Disasters such as floods or contamination of the environment with radioactive wastes or chemical spills, or individual actions that put others in direct jeopardy are situations in which individual rights to autonomy in health care may temporarily be overridden. Thus, while nurses must be aware of the need to preserve the rights and responsibilities of clients, they must also be aware of the demands of justice and fairness.

Making sense of these tensions in the practice world of patient/client care and in the public arenas such as public policy making is a major challenge for all of us in nursing who are attempting to become clearer about our obligations to present and future clients. Individual health and the health of the environment in which individuals, families, and groups interact and transact is at stake. We need policy approaches that relate concern for people to concerns for the environment as visualized at least theoretically in philosophies of public/community health. We have barely started looking at questions which relate environmental health concerns to individual health concerns - a subtopic that might be called an 'ecological ethic'. A broad issue involving individual and public health is the allocation of health care dollars to health service programs for people as opposed to programs for environmental clean-up.

Ethical Reasoning and the Political Domain

Ethical reasoning and the exercise of "moral imagination" in the political domain include three different systems levels incorporating the interface of politics and ethics in nursing. The first is the "micro" political level such as the politics of patient care decision making. This level is represented by the nurse/client/phyisican triad in which there may be conflicting needs and interests requiring difficult choices among the best interests of the client and power issues between nurses and physicians. The second is the "macro" political level exemplified by development of public policy for financing of health care delivery systems, or for treatment of the terminally ill. A third level is the "intermediate" political level of institutional/organizational policy making such as development of "limited treatment" or "supportive care only" policies, or delegation of decision making responsibilities to ethics committees in acute and long term care facilities.

Participants in all three levels should at least be involved in procedural activities to assure more reasoned decision making. Decision making with and for clients should be accomplished in a shared decision-making model. Decision making processes should at least take into account (1) development of the most adequate data base possible recognizing that in many instances the data are not available or there are disagreements as to the so-called "facts" of the situation, (2) discussion of the ethical principles and values at stake such as personal autonomy, avoiding harm, honesty, keeping promises, or justice and how they are enhanced or negated by proposed decisions or policies, and (3) assessment of the direct and indirect consequences for all who are affected by policy proposals.

One way to incorporate the ethical/political interface at any system level of intervention in the spirit of an ethic of prevention is suggested by social scientists Warwick and Kelman (1976). They discuss four areas of intervention which can be applied at any nursing and health care system level so that ethical concerns and questions may be addressed before decisions are made, actions taken, or policies developed and implemented. As nurses we have opportunities to raise such considerations in our agency's or our community's policy review mechanisms, whether in proactive policy development or revision of existing policies. The four areas may be related to policy development where conflicting needs and interests are evident and issues of power are inherent. The four areas are (1) the choice of policy goals which maximize certain values and minimize others. An example is prospective reimbursement systems which have cost containment as their major purpose thus maximizing economic values and minimizing human values of respect for individuals; (2) the definition of the target of change; that is who is asked to change--clients, providers, or caregivers? And how are the targets of change to be involved in the process of change? (3) the means chosen to implement the policy. These means may range from coercive to facilitative where the freedom of choice of individuals is a major consideration and respect for individual autonomy may be enhanced or negated; and (4) consideration of direct and indirect consequences of a proposed policy to the greatest extent possible, such as evaluating costs (an example of a concern for distributive justice) and emotional/psychological consequences predicted for all who will be directly and indirectly affected by the policy whether individuals, families, the community, or caregivers.

Raising these questions and concerns before taking action is in the best interest of preventive ethics which when combined with sensitivity to political power considerations could lead to different policy options than are evident without such reflection and discussion. Although it will not lead automatically to one ethically acceptable decision or policy, such analysis will rule out certain decisions or aspects of policy that cannot be justified morally, for example ignoring whether a policy enhances individual autonomy or considers fairness issues. These aspects may be ignored in the heat of strategy development battles in traditional political arenas. Think about a recent or proposed policy change in your own institution and determine to the greatest degree possible what changes there might be in the policy if these areas of ethical concern were addressed explicitly; that is, going beyond technical and economic feasibility to what might be or might not be justified from an ethical perspective.

"Real" World Efforts at the Interface of Ethics and Politics: Justice Considerations

The President's Commission Report (1983) entitled, Securing Access to Health Care (1983) contains conclusions which could be viewed as demonstrating the interface of political and ethical considerations for the purpose of achieving more equitable access to health care for all. These conclusions could be used for public discussion and as a foundation for development of specific public policies. The conclusions are:

1. "Society has an ethical obligation to ensure equitable access to health care for all. This obligation rests on the special importance of health care's role in society in relieving suffering, preventing premature death, restoring functioning, increasing opportunity, providing information (and education) about an individual's condition, and demonstrating empathy and compassion." Society was considered by the Commission to be the American community of individuals, families, groups, organizations, and institutions.

2. Societal obligation is balanced by individual obligation in which individuals pay a fair share of the cost of health care and take reasonable steps to provide for care without excessive burdens, recognizing that individuals cannot be solely responsible for their own health.

3. "Equitable access to health care requires that all citizens be able to secure an adequate level of care without excessive burdens." An adequate level of care was considered by the Commission as a floor below which no one ought to fall, not a ceiling above which no one may rise. This would require considering the value of various types of health and nursing care in relation to each other as well as the value of health care in relation to other important societal needs such as defense and education.

4. Ultimate responsibility for ensuring that society's obligations is met rests with the Federal government through a combination of public and private sector arrangements when market, private charity, and government efforts at state and local levels are insufficient to achieve equity.

5. "The cost of achieving equitable access to health care ought to be shared fairly. The cost of securing health care for those unable to pay should be spread equitably at the national level and not allowed to fall more heavily on particular practitioners, institutions, or residents of different localities. Those with greater financial resources should shoulder a greater proportion of costs. Government resources should be used first to achieve equitable access for all before they are used to

secure more care for people who already receive an adequate level of care.

6. Efforts to contain health care costs are important but should not focus on limiting the attainment of equitable access for the least well served portion of the public such as the poor and otherwise least advantaged. Cost containment measures that increase existing inequities or impede the achievement of equity are unacceptable from a moral standpoint.

The concept of justice as equity is problematic in itself because it is viewed differently by different individuals and groups. There is no overall consensus in our society on the concept of justice as equity. One of the overall considerations of distributive justice in health care is that people ought to be treated equally in the distribution of costs and benefits of health and nursing care. When this is not possible, we must identify the relevant moral reasons for treating people differently. Is it possible to develop compelling moral reasons for treating some population groups of patients differently such as those who have AIDS? Or treating some categories of health professionals differently in terms of remuneration?

Several different concepts of justice point to why we are foundering and confused in our seach for justice and equity in health care. Program planning and implementation should take seriously the underlying values and principles such as respect for individual persons and distributive justice which advocates equal or fair distribution of burdens and benefits. For example, the Code for Nurses states that nursing care should be based "solely" on need. This criterion is congruent with the person-centered ethic and the traditional medical ethic of doing everything possible for the individual patient. At the same time we know that doing everything technologically possible for the dying individual may be disproportionately burdensome compared to potential benefits. Treatment in some instances may be more cruel than humane, and in our society we agree that there is a fundamental human right not be be tortured. Whose needs are being met in such a situation, those of the individual patient, or those of the caregivers who have been educated to do everything possible? Allocation of resources in health care on the basis of need has other limitations such as who decides what defines need. Should demands and preferences also count as "needs?" In some circumstances this might mean swallowing up all of our resources in a limited area. There is almost no limit to the funds that could be devoted to potentially beneficial care for some diseases and disabilities and their prevention. Adding environmental factors to the equation makes the likelihood of exhausting societal resources even more probable. Additionally such assessment must be put in the context of other societal priorities such as defense and education.

Other justice-related criteria used to determine the distribution of burdens and benefits of health care include allocation on the basis of the ability to pay for care, or on the basis of merit such as the patient's past or potential contributions to society. Committees that made decisions about allocation of renal dialysis machines in the late sixties found the idea of merit or social worth of the individual as a basis for resource allocation to be morally worrisome. The idea of merit and ability to pay for health care is resurfacing strongly in the 80's. An example is the Arthur Anderson report on Health Care in the 1990s (1984) which describes trends for consumers such as: an increase in patient payments, cutbacks in funding for health care of specific groups covered under governmental programs or for specific health problems, and restrictions for patients with private coverage. Even so, additional levels of service will be available to those willing to pay for them (Anderson, 1984). The ethical criterion of equity requires that people in similar situations be treated similarly. Some of the questions which arise in nursing related to this criterion include: How should nursing time and expertise be allocated most equitably? What elements should be considered when a community nursing agency with limited mechanisms for reimbursement identifies several vulnerable populations requiring nursing services? What, if any, are the relevant moral differences that justify different levels of service or none for some vulnerable individuals or groups?

One of the major candidates for a comprehensive and adequate theory of justice in our society has been envisioned by philosopher, John Rawls. Rawls (1971), in his theory of justice as fairness, views justice as the moral basis of society and claims that society has the obligation to structure itself in such a way that there are equal liberties and opportunities to have access to social goods such as wealth. He argues that these are the principles upon which societal arrangements would be based if none of the decision makers knew their own position in society; that is, whether they would be rich or poor, male or female, healthy or unhealthy. The least advantaged, as the criterion group(s), are to benefit whenever there are benefits for the more advantaged. Self-respect is recognized as a primary social good and conditions that undermine self-respect are to be avoided. Rawls suggests that self respect is the most important primary good. 'Primary goods' are those which every rational person is presumed to want, things that normally have a use whatever a person's rational life plans and goals. Rawls says that "without self-respect nothing may seem worth doing, or if some things have value for us, we lack the will to strive for them." Therefore we wish to avoid at almost any cost the social conditions that undermine self respect. This consideration raises additional ethical concerns about the conditions under which health care is delivered which often seem inhumane, uncaring, and lacking in respect for individuals.

In all of these notions of what constitutes justice, one sees the tension among the three levels of interaction: the autonomy and rights of individuals, the rights of others in society, and the interconnectedness of all of us in our society and on the globe. This is so from both personal and public health perspectives and in the environmental health issues. Examination of the ethical dimensions of policy and proposed legislation raises issues about our technical and economic capabilities in light of what we should or ought to do in developing more morally adequate health and nursing care systems for both caregivers and clients. Such discussions and decisions take place in what Reinhold Neibuhr, a theologian, called the "twilight zone." This is the realm of politics where ethical and technical issues meet, a realm familiar to all nurses who have struggled for reform and change in the delivery of health care throughout history. If need is to be the underlying moral justification for treating people differently in delivery of nursing care, then policy and laws affecting delivery of nursing care to people should be put to this moral test. The question of what might be a "just" distribution of nursing services across the care spectrum for individuals, groups, and communities can be answered only with discussion of some very uncomfortable and ambiguous issues. This requires identification of the responsibilities and obligations of nursing, other health professions, and the society which we claim to serve. There must be appropriate consideration for those who are acutely, chronically, or terminally ill, vulnerable groups, the worried well, and the well.

One effort to have public dialogue on ethical concerns in health care was the Oregon Health Decisions Project (1985) which was conducted in the early 1980s. A series of public meetings was held in communities throughout Oregon which resulted in development of ethical principles for making health policy decisions. Examples include the following: (1) through open debate, society should decide what constitutes the level of health care that should be guaranteed to all; (2) adequate, universally guaranteed health care will not include everything available in the health care marketplace; and (3) community concensus should guide policies for rationing health care services, allocating resources to health, and controlling health care costs. Goals for Oregon included developing a fair and open means for making health care rationing and allocation decisions, reducing waste and inefficiency in the health care system, protecting the dignity and autonomy of sick and dying patients, defining the "adequate" level of health care that should be available to all Oregonians, and strengthening disease prevention and health promotion efforts. These are congruent with efforts being made in other states such as Minnesota to examine the ethical and economic cost of high technology and its distribution compared to preventive efforts in health care. These states give maternal and infant health care a priority for attention as an effective avenue for prevention and prophylactic treatment.

Care of the terminally ill is another area of nursing in which nurses and clients confront the interface of ethics and politics. Recommendations have been made by one group studying this issue (Bayer, et al., 1983) that even though we spend what seems like an inordinate amount of health care dollars on care of the terminally ill, it does not automatically follow tht we ought not to spend large amounts of health care dollars on this group. Recommendations were:

1) there should be careful selection of patients admitted to intensive care,

2) terminally ill patients and their families should be more involved in shared decision making; and

3) the hospice option should be promoted for the terminally ill, recognizing that funding for such care has become more limited in recent years because of hospice funding legislation and prospective payment for Medicare patients.

Summary

The interface of ethics and politics in the world of nursing is inherent whether one is in education, hands on practice, administration, or research. Frameworks have been presented for integrating the ethical dimension into situations such as policy development where political/power dimensions also exist. The President's Commission conclusions on access to health care, the Oregon Health Decisions Project, and recommendations for care of the terminally ill are examples of how the interface of politics and ethics offers opportunities to develop more morally adequate policy both reactively and proactively.

In order to deal with what some Minnesota nurses called "the most important ethical issue facing nursing today", that is, the allocation and rationing of scarce nursing and health care resources, we must pay attention to the fate of ethical principles such as respect for persons and distribute justice and the political implications of attempting to develop more ethically adequate institutional and public policy. Wherever ethics and politics interface in the "real" world, the implications and opportunities for nursing education, administration, practice, and research are mind-boggling. As members of the nursing community, we must promote reflective action in all domains of nursing so as to take into account both ethics and politics. This is becoming increasingly difficult to accomplish in our survival-oriented health care systems of today.

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Pluralistic Ethical Decision-Making

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Ethical Theory

Three ways of thinking that relate to morality and ethics are discussed by Frankena (1973). These three approaches are considered different study traditions in the field of ethics. The first tradition or way of thinking about ethics, is called descriptive ethics. A descriptive ethicist is one who is concerned with how people actually behave. The goal is to describe and explore the phenomenon of ethics that is acutally present in a given situation. The second tradition of ethical thinking is called normative ethics. The normative ethicist asks what is right, what is good, or what is obligatory. The normative ethicist is concerned with the rationale for action and with an appraisal of the decision-making process that occurred before the action was taken. The normative ethicist must be ready to give reasons for his judgement about action; in other words, he is concerned with the process of justification. The third study tradition of ethics is concerned with meta-ethical thinking. Meta-ethics is basically concerned with the semantics of meaning and is sometimes described as analytical thinking. Meta-ethics is not concerned with action decisions in particular situations. Rather, it is concerned with answers relating to logic and semantics.

Davis and Aroskar (1978) believe that the study tradition of normative ethics is the tradition most useful in a program of study in bioethics for a professional nursing curriculum. The professional nurse must often debate with self or with someone else about what is good or right in a particular patient concern or as a general principle. The latter type of thinking relates most directly to the normative ethics study tradition.

An ethicist is one who is engaged in an ongoing critical reflection of morality. A critical reflection on morality can take place at several levels of discourse, discourse with one's self or with another. Four levels of ethical discourse are discussed by Aiken (1962). These include first, particular judgement; second, moral rules; third, moral principles and values; and fourth, reasons for being moral. The third, moral principles and values, and the fourth, reasons for being moral, are more useful for professional nurses as they justify their decisions.

Deontological Ethics

Normative ethics is considered as comprised of two major schools, the school of deontological ethics and the school of teleological ethics. Deontological ethics or the ethics of formalism recognizes the existence of prima facie duties or obligations. Such duties include the fulfillment of promises, and payment of debts, and the telling of truth. Such duties admit of no exception regardless of the circumstances in a particular situation. The deontological system holds that the rightness of an act is either not entirely determined by the value of its consequences or is not at all determined by the value of the consequences. The basic principle of deontological ethics is that the ethical act does not entirely depend on the consequences of the action. Rather, the ethical act is that act which is in agreement with one's duties and/or obligations.

In order to know whether an act is right or wrong, one needs to determine whether it is in accordance with a valid moral rule. Ross (1930) believed that the rightness of an act may in part be determined by the goodness of its consequences, but it is never wholly determined by such good consequences. Deontological ethics maintains that there are duties or obligations affecting action which have moral validity independent of the consequences of individual actions. One must act in accordance with these duties and obligations.

The principle of universalizability means that an action principle or duty obliges everyone without exception. Another important principle of an action principle or duty is that it is necessary. By the word necessary is meant that the righness or wrongness of the action has no relationship to the nature of the world in which the doer finds himself or herself.

Teleological Ethics

Teleological ethics judges an action as either morally right or wrong by judging the consequences of the action according to Brody (1976). Teleological ethics is also called consequentialist ethics. The teleological ethicist denies that the nature of the action itself is either morally right or morally wrong. Rather, the consequences of the action alone determine the moral worth of the action. The teleologist's primary objection to deontology is the idea that obligation or duty can in any way be self-evident. If duty or obligation is self-evident, then how are we to explain irresoluble differences of opinion about what ought to be done? The rise of the teleological ethical school came about primarily in response to this objection to deontology.

Utilitarianism is that form of teleological ethics which utilizes the single ultimate principle. In other words, utilitarian ethics is a kind of consequentialist ethics. Utilitarian ethics is the largest branch of ethical theory within the teleological school of ethics. The utilitarian single exceptionless principle is that the right action is that action which produces the greatest amount of pleasure or good for the greatest number.

The major assumption that separates teleological ethics from deontological ethics is that moral issues can be determined by empirical calcu-

In the teleological ethical system, moral significance is always future-oriented. In other words, no moral significance can come from historical duty or obligation. In discussing teleological utilitariansim, it must be emphasized that the standard of value for judging must be impartial and universalizable (Taylor, 1975). Impartiality is best viewed as the fact that everyone counts as an equal unit of one. Universalizability is the assumption that everyone in similar circumstances would do the same act.

Rawls (1971) viewed the structure of an ethical theory as basically determined by how it defines and connects the notions of the right and the good. The right refers to the nature of the action itself and the good refers to the consequences of the action. The simplest way of relating the two basic notions is taken by teleological theories; the consequences are defined independently from the action, and then action is defined as that which maximizes the desired consequences.

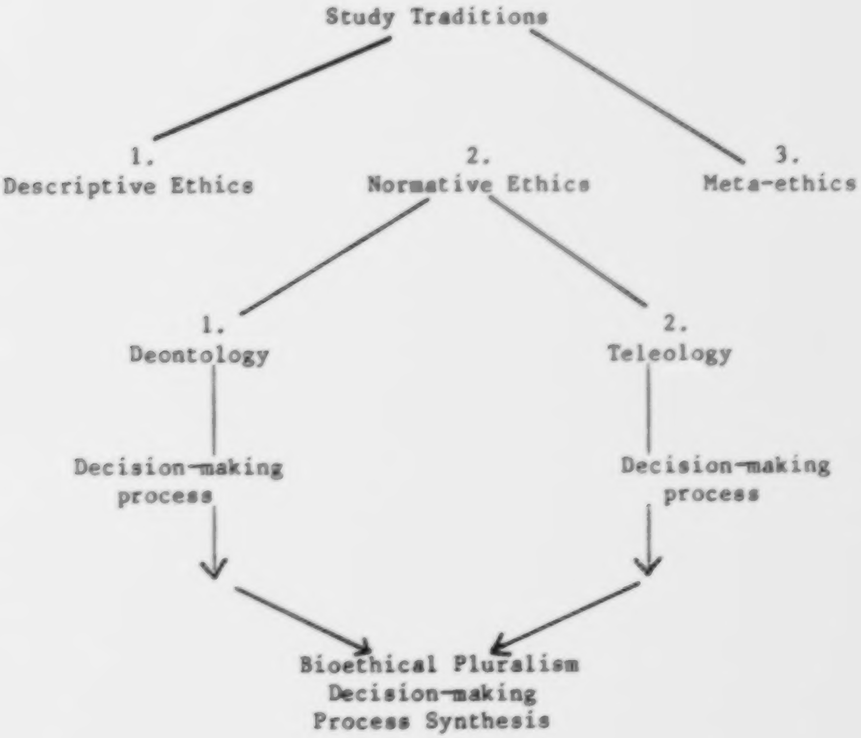
Bioethical Pluralism

Very few, if any, professional nurses make decisions according to either pure deontological ethical reasoning or pure teleological ethical reasoning. In everyday realistic situations, people are concerned with both the means and the ends of their actions. Means of action can be conceptualized as the "right" or the nature of the action. The ends or consequences of the action can be viewed as the "good," the "good" that results from the action.

Does the professional nurse originally isolate the ethical thought process on means rather than ends, or on ends rather than means? As most people in real situations do when faced with a need to make an ethical decision, professional nurses are concerned with both means and ends simultaneously. Bioethical pluralism refers to the simultaneous concern with both means and ends. Bioethical pluralism denies that the morality of an action is determined either by consideration of the means of the action alone or by consideration of the ends of the action alone.

Bioethical pluralism is a term preferred by this writer as more useful decribing the actual ethical system in use by most professional nurses. Figure 1 indicates that the pluralistic ethical system is not teleological in nature, nor is it truly considered deontological.

Figure 1. Theoretical conceptual framework for deriving a pluralistic decision-making model.


Study Traditions
1.
Descriptive Ethics
2.
Normative Ethics
3.
Meta-ethics
1.
Deontology
2.
Teleology
Decision-making process
Decision-making process
Bioethical Pluralism Decision-making Process Synthesis

Ethical Decision-Making

Professional nurses are constantly and deeply involved in situations requiring ethical decision-making. Dependence on the American Nurses' Association' professional Code for Nurses (1976) alone will not provide nurses ethical answers in specific patient care situations. Therefore, lation. One can weigh the value of a given consequence or combination of consequences against a different consequence or combination of consequences.

Broad social and cultural changes have affected nursing structures and decision-making processes. Dominant political scenes now include human rights and individual autonomy. Pluralism and personal freedom are highly espoused. At the same time, there has been an increase in bureaucratization and development of complex social institutions to deal with public problems. The complex health care delivery system is an example.

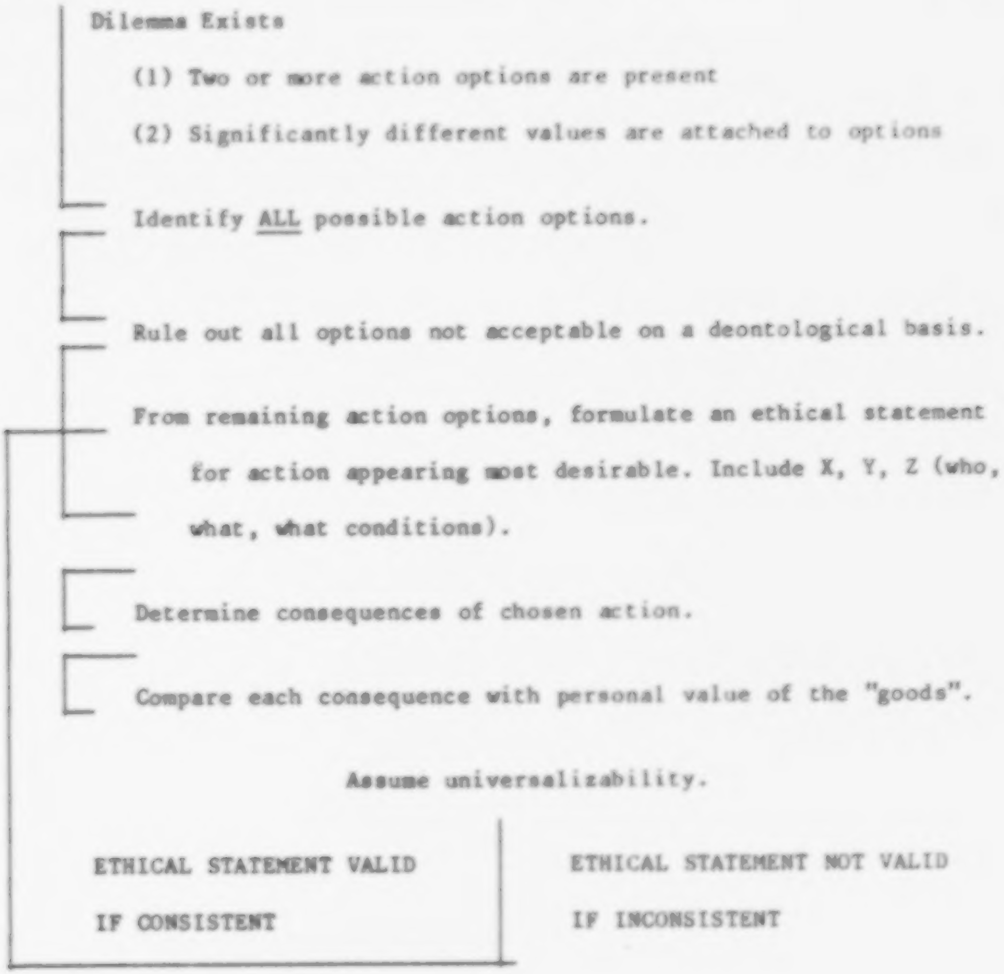
The content of the concept of bioethics is vital and dynamic because morality cannot be identified without some reference to the context of action. This writer denies an absolute fact-value distinction. Expansion in knowledge such as professional nurses witness in relation to rapid technological advancement must inherently be involved in moral decisions. Knowledge increases our options and moral or ethical behavior reflects the options chosen. Fact is always changing as our knowledge base changes. What was moral at one point in our history of understanding could now be immoral because of a change in our base of knowledge. One result of this latter veiwpoint is that fact and value are part of morality and, therefore, we cannot hope to find exceptionless and absolute rules of morality. It has become essential that professional nurses develop skills and a comfort level with an ethical decision-making process that will be useful over a span of time regardless of the changes in the knowledge base upon which they function.

Some basic questions arise as one attempts to define a useful pluralistic decision-making model. The first question explores whether a rational decision-making process that is powerful enough to determine priority in the face of conflicting value interests actually does exist. The second question concerns the possibility of establishing such a reasonable decison-making process by rational methods of inquiry. The purpose of normative ethics is to use inductive and deductive logic to arrive at reasonable ethical action decisions.

Pluralistic Ethics Decison-Making Model

Brody (1976, p. 11, A-2a) developed two distinct ethical decision-making processes, the first for the teleological ethicist and the second for the deontological ethicist. His models are simple, clear and concise. They, therefore, possess characteristics which are essential for a model if that model is to be useful for the professional nurse. As this writer has expressed earlier, however, practicing nurses do not seem to reason in a pure deontological manner or in a pure teleological manner. Figure 2 represents a synthesis of Brody's original models. The synthesis should be more useful for the professional nurse because it allows for simultaneous concern with the nature of the action and the consequences of the action.

Figure 2. Pluralistic ethical decision-making model*



Dilemma Exists

(1) Two or more action options are present

(2) Significantly different values are attached to options

Identify ALL possible action options.

Rule out all options not acceptable on a deontological basis.

From remaining action options, formulate an ethical statement for action appearing most desirable. Include X, Y, Z (who, what, what conditions).

Determine consequences of chosen action.

Compare each consequence with personal value of the "goods".

Assume universalizability.

ETHICAL STATEMENT VALID IF CONSISTENT

ETHICAL STATEMENT NOT VALID IF INCONSISTENT

On cycle return in case of invalid result:

(1) Ethical statement may be reformulated modifying the conditions.

(2) Alternate action options (still available after being ruled in) may be explored, going through all remaining steps.

Remember, the decision to take no action is in itself an action option.

***An original synthesis of the deontological and teleological decision-making models of Brody (1976). May not be reproduced without permission from author.**

Some basic skills are needed before one engages in ethical decision-making regardless of the decision-making model utilized. The most obvious skill is recognition of an ethical dilemma when it exists. Inherent in this skill is the ability to separate true ethical or moral dilemma from those dilemmas which are really nonethical or nonmoral. Power and/or authority struggles are often mistakenly labeled as ethical dilemmas; so are technical differences of opinion.

Potential ethical dilemmas for the nurse have to be analyzed for the presence of at least two variables. The first variable relates to the number of action options truly available to the nurse. If it is truly only possible for the nurse to take one action, then no dilemma exists. More than one real action option must exist before an ethical dilemma can be said to exist. The action option that is most frequently overlooked is the option to take no action. Taking no action whatsoever is often a very powerful action option and must never be forgotten.

The second variable that must be analyzed when determining whether or not an ethical dilemma exists is the value weighting the nurse would give to the consequences flowing from the various action possibilities. If the combined consequences of action A have weighted value equal to the combined consequences of action B, etc., then it is doubtful whether a true ethical dilemma exists. For example, when two nurses have differing opinions about how best to position a patient for a given procedure and no scientific basis exists for defending one opinion over the other, it is very doubtful whether an ethical dilemma exists. A power struggle or dilemma may ensure, but an ethical dilemma is just not present.

Once it has been determined that an ethical dilemma does in fact exist, the nurse proceeds to make a list of all possible action options. It is rare when only two actions are possible. Make every attempt to make the list of action options exhaustive. Often a third or fourth action option will prove more useful than the first two possible actions occurring to the nurse. Often we cut off our thinking after coming up with two action options and carry on an either-or type of struggle (Brody, 1976, p.9).

The nurse now needs to compare each and every action to his or her set of a priori moral principles or rules. These rules exist because of predetermined duties or obligations. The nurse who has difficulty determining his or her own a priori ethical rules could probably benefit from various value clarification strategies which are so popular today. As one example, one action option in a given patient situation might involve the nurse giving the patient a truly lethal dose of a medication. However, the nurse recognizes and accepts an a priori principle which states that one may never kill except in self-defense. This particular nurse would, therefore, have to rule out the action option which would require the giving of a lethal dose of a medication. Each listed action option must be screened through the individual's own list of predetermined moral or ethical rules. Eliminate those action options which violate individual moral rules or principles.

At this point in processing the dilemma, one action option will seem to stand out as the most desirable. It would seem only reasonable to acknowledge this human response. So choose the most desirable appearing action option and formulate a moral statement. The ability to formulate a moral statement is a skill which requires understanding of the principle of universalizability. A formula for a moral statement is, "In situation X, person Y ought to do thing Z" (Brody, 1976, p. 6).

The nurse ought not administer a preoperative medication to a patient who has not expressed informed consent for the proposed surgical procedure. This looks like a fairly adequate ethical or moral statement. The nurse is Y; administering the preoperative medication is Z; and the rest of the statement seems to be X. But the conditions X are really not complete. We do not expect infants or incompetent adults to give informed consent. Therefore, the moral statement would have to be modified by perhaps inserting the words competent adult in place of the word patient.

The principle of universalizability would mean that all nurses ought not administer preoperative medication to any competent adult who has not express informed consent, etc. The nurse cannot put the personal self "I" into an ethical statement. This would violate the principle of universalizability and reduce the statement to a statement of personal option contingent upon the circumstances of the time.

The next step of the decision-making process is to determine and list all of the possible consequences if everyone were to follow your proposed ethical statement. It is important that both immediate and longterm consequences be defined. We all tend to be mainly concerned with the immediate consequences and tend to forget to explore the ramifications for the future. It is probably humanly impossible to define all consequences, but we should attempt to "reduce uncertainty to manageable proportions" (Brody, 1976, p. 10). Undoubtedly, ten years from now when one looks back at ethical statements that one has formulated, some will appear obsolete or untrue. That does not mean that the statement was not valid when it was formulated. It is an indication of the reality that the body of knowledge upon which ethical judgements are made will change with the passage of time. As the facts as we know them change, so may our ethical determinations change.

Once one has determined all possible consequences to the best of one's ability, it is time to proceed to the next step of the decision-making process. Each of the consequences must be compared with the individual's value set. Once again, it is imperative that nurses individually develop insight into the relevant health care related values of their total value set. Since the nursing profession is inherently a human-to-human interaction, a large proportion of an individual's total value set is relevant. Values relating to autonomy, paternalism, truth-telling, justice, and confidentiality are just a few of the relevant values.

Values clarification techniques again might prove useful in aiding individual nurses to gain the needed insight.

If the possible consequences do not seriously violate the personal value set, the proposed ethical statement will be congruent or valid, and the individual should feel free to take action as contained in the ethical statement.

It is very common for one or more of the consequences to come into conflict to some degree with the value set. When this happens, the ethical statement is considered incongruent or invalid. As indicated in Figure 2, there are two basic methods to utilize when incongruence occurs. The ethical statement may be tightened up by modifying or clarifying the conditions, X, in the statement. If modification of the statement cannot eliminate major incongruencies, then it may be necessary to choose another action option. When a different action option is chosen, it must itself be processed through all the remaining steps of the decision-making model.

The pluralistic decision-making model will obviously not guarantee group consensus among members of a nursing or health care team. But consensus probability is certainly increased when compared to a process which involves the simplistic sharing of opinions and feelings about what ought be to done in a given patient situation. The individual nurse, furthermore, emerges knowing much more about his or her personal value set and can contribute much more at a rational level in ethical decision-making.

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Compassion, Technology, and the Law: The Legal Perspective

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Compassion and technology - the nursing profession encompasses both these things. The law, perhaps neither. The law is in fact only a process - a process for dispute resolution. Only when the interests, compassion, and technology appear to conflict must the law become involved. Through the legal process, the rights, duties, and interests of patients and those of nurses in each of the attributes can be balanced and apportioned. The law provides both the framework and the procedure to accomplish those ends.

It is clear that every patient is unique, every patient's needs are unique and thus the responsibilities of the nurses and the nursing profession likewise unique. Interestingly and surprisingly, perhaps the law has the ability to respond to those unique needs.

To illustrate the role of the legal process and the ability of the law to provide a useful framework, I am going to focus my remarks on the protection of patient autonomy in the decision making process. Health care decision making brings the nuances of these aspects of twentieth century life into focus. Through the legal process we can devise a path for the peaceful coexistence of compassion and technology.

The law has long recognized the role of patient autonomy in the decision making process. By recognizing the patient's rights to decide, both compassion and technology can be relegated to an appropriate place in patient care, the weight provided to each declared by the patient himself. There is clearly no fixed proportion for these elements cited by court cases or by statute. Patient autonomy as a legal principle is most likely to guarantee a just result - the decision resting with the individual who will bear the personal result most heavily. The patient's right to decide is often mistakenly called the patient's right to die, but in fact it is much broader than that. The right to decide encompasses the right to consent, as well as the right to refuse, and the right to choose between available alternative treatments.

Why has so much of the focus been on the patient's rights to die? I believe it is because that area raises the most unsettling questions for us in aiding the patient in making these determinations.

Let me introduce three patients who were central figures in three important legal cases (Conroy, 1985; Bartling, 1984; and Foody, 1984) to illustrate how the right to decide is effected in health care. The first one was named Claire Conroy. She was an 84 year old nursing home patient with severe organic brain syndrome and a variety of other very serious diseases: chronic foot, leg, and hip ulcers; urinary tract infections;

arteriosclerotic heart disease; hypertension; and diabetes mellitis. Except for minor movement, she was unable to move or to speak. She lay in bed in a fetal position. She sometimes followed people with her eyes but often simply stared blankly ahead. Her general physical appearance was very withered. Mrs. Conroy was totally dependent on an NG tube for nutrition and hydration. Her nephew was her only living relative and he sought to have the feeding tube removed, understanding that the removal would result in her death. The nursing home refused per the doctor's order, and her nephew went to court for a decision that it was permissible and legal to remove the feeding tube.

The second patient was William Bartling. He was a 70 year old man in California in a hospital with several serious and life-threatening illnesses including chronic obstructive pulmonary disease, an aortic aneurism, coronary artery disease, severe anxiety depression, and probable lung cancer. He was surviving on a respirator in a respiratory intensive care unit (ICU) because of a collapsed lung, the result of a lung biopsy. Both patient and his wife requested that he be removed from the ventilator. There was no question that this would have had the effect of causing his death within a short time. The hospital and the doctors refused to disconnect the ventilator, and the family went to court for an order that the ventilator should be disconnected.

The third patient was named Sandra Foody, a 42 year old patient with advanced multiple sclerosis of twenty year's duration. She suffered a respiratory arrest because she aspirated some food, and as a result she was placed on a respirator. The family sought her removal from the respirator which would have had the likely effect of causing her immediate death.

The legal issues of these cases seem to be similar, centering on the patient's right to refuse treatment. But we, as nurses, recognize how unique these patients are. Their ages vastly differ, their diseases differ, their family situations differ. Sandra Foody was single, with living parents. Ms. Conroy had never been married; her only living relative was a nephew, and Mr. Bartling has a very involved spouse. Each of these patient's situations was extremely personal and thereby became profoundly singular in the legal sense as well.

It is obvious that there are many philosophical, legal, and ethical considerations (perhaps we might say conflicts) inherent in these situations. Such cases may be common for the nurse, but are uncommon for the individuals directly involved. These patients, and the decisions they confronted, raised profoundly disturbing questions. The questions do not lead directly to any easy answers nor to any ideal legal solutions. As medical technology makes it possible to live longer, patients and their families are increasingly asserting their right to choose whether they will have or not have dependence on that medical technology in the form of treatment. The President's Commission on the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research noted:

> Once someone realizes that the time and manner of death are substantially under the control of medical science, he or she wants to be protected against decisions that make death too easy and quick as well as those that make it too agonizing and prolonged (President's Commission, 1983).

Professional people, we think, are all too susceptible to the elitism and power which seem inherent in our positions. We can easily slip into the role of deciding these questions for others on the basis of what, in our opinion, is best for them. That philosophic outlook is referred to as paternalism (Childress, 1980). Many wrongly assume that the answers to these dilemmas are really simple. The life and death decisions that have come to our attention can only be undertaken with a profound sense of humility and reserve. These decisions raise moral, social, technological, philosophical, and legal questions which in many instances have no universally accepted answers.

Our attempts to wrestle with these issues may be imperfect, but that in many ways defines the human condition. These decisions should be hard, because life often challenges us with hard choices, for which there are no ideal solutions. In this, notwithstanding modern technology, our present situation does not differ from the questions put to previous generations.

The law has been fairly consistent in recognizing the right of the patient to decide about this treatment; this concept is not new. An oft-cited decision of Justice Cardozo in 1914 noted, "Every human being of adult years and sound mind has the right to decide what shall be done with his own body..."(Schloendorff, 1914). That's autonomy. To understand how autonomy is given effect in patient decision making, we must look first at whether or not the patient is competent. Competency is measured by several factors. The patient must have the capacity to understand the information that is being provided to him; he must be able in some way to communicate his response to that information; and he must understand the ramifications of his decision. That does not mean that he has to be able to write or sign his name on a specific line on a special form. That does not mean that he even has to be able to speak, for, after all, we, in nursing understand that communication can take many forms. A nod of the head or wave of a hand speaks just as loudly as written or spoken words. Once the patient has been found competent, (and there is a presumption of competence), he has the right to choose for himself whether or not he will have treatment. A refusal is every bit as much of a choice as is consent. And the patient has the right to refuse even if the refusal of the treatment or the choice that he makes will mean that the patient will die. As nurses we may feel uncomfortable when we see a patient making certain decisions - not the decision we would make for ourselves, not the decision we would like the patient to make for himself, and in fact not the decision which is likely to lead to a positive physical result. But that is the decision the patient has the right to make.

The incompetent patient shares this right of the competent patient - the right to decide. The question for the incompetent patient, however, is who is going to exercise this right on his behalf and on what basis. *Be aware that it is easy to abuse the competency determination. It is all* too easy when the patient makes a decision that is different than what was recommended by the health care providers to say, "Oh well, that patient is incompetent anyway."

An example may highlight the problem. Mrs. Candura (Lane, 1978) had diabetes and gangrene of the right foot and lower leg. On two occasions, within a very short period of time, she consented to two amputations, a toe and part of her right foot. Shortly thereafter, the doctors recommended amputation of the leg. At this point apparently Mrs. Candura felt she had had enough. She emphatically refused. Upon her refusal, the physicians put her competence in question. No one, however, had questioned her previous competence to consent.

The competency determination may also be distorted when dealing with the "undesirable" patient; e.g., the patient with poor hygiene, or a substance abuser. With these patients, often a refusal is too quickly accepted and their competence not questioned.

Futhermore, we must determine whether the patient has all the information of material interest to him in order for him to make an informal refusal. An example of such a patient recently came to our attention. A "personally unappealing" patient had lung cancer and had been living in a nursing home. Chemotherapy was proposed. Very shortly thereafter, a note appeared on the chart that the patient had refused treatment and was competent to refuse. The nurse questioned the conclusion. After investigating, they became patient advocates. They determined that the patient had been informed only that the treatment was not going to cure her cancer, but would only be palliative. But she was not given the information that while being only palliative, the treatment also would allow her to stop using oxygen, and use of oxygen was blocking her return to the nursing home that she viewed as home. Once that information was provided to her, she consented to the treatment.

The basic procedure whereby we insure the patient's right to consent or the right to refuse is through the informed consent process. The informed consent process has its legal underpinnings in early English common law. Basically, the law said if you touch a patient without the patient's permission, it would be a battery, an illegal touching. The informed consent procedure can be viewed as a partnership between the physician and the patient. The physician provides the information and the patient provides the consent or refusal to consent. There are several factors in an informed consent. The patient must be told:

1) his diagnosis,
2) his prognosis,
3) what the proposed treatment is in language the patient can understand,
4) alternative procedures,
5) all the benefits and risks of both the proposed treatment and the alternative treatments, and

6) the risk of doing nothing.

That may sound like a lot to have to tell the patient, but that permits the patient to have that material information that he needs in order to make a decision. Without this, he is not making a decision based on any knowledge. I think you should know that there has never been any reported liability against a health care professional for disclosing too much information, although that seems to be a generalized fear that the health care community has.

The consent form that we deal with in our agencies and institutions, that piece of paper that very often we have the patient sign, is not in fact the consent. The consent is a process, a relationship betweem the patient and the physician, or between the patient and the health care provider, and all that consent form can really be is evidence that the process took place.

For professionals, it is easier to accept the patient's right to informed consent in areas about which we are less familiar. I talked to you about patients on a respirator, and if you don't work in the critical care area you will likely nod and agree that the patient has the right to decide if he wants to come off the respirator, even if it means he is going to die. But when it is in your own area of expertise, or your patient, it becomes personal and extremely difficult. If you are a home health nurse and the patient that you have been visiting three times a week is refusing to take the medication that you so carefully left for him in the egg carton with each day labeled, you will be the first person to say, "Well, do I have to continue going to that patient's home if he is not going to take his medication as he said he would?" Or the GYN nurse may agree with patient autonomy for the patient who wants the respirator turned off, but when the patient gets back a positive pap smear and says, "Well, I know I have cervical cancer, but I don't want any treatment," that nurse may say, "Do I have to let the patient come back to my clinic?" This is a very human phenomenon, a tremendous and understandable reluctance on our part to protect our patient's right to decide contrary to our personal and professional inclinations.

The other matter in which informed consent has become very crucial and easily abused is in experimental procedures. Consider Barney Clark and the heart patients that have followed, or Baby Fae, and cross-species transplantation. We are talking here about patients who, by definition, really have very few viable treatment options open to them. The doctors who have developed the procedures want very much to try them out on human beings. Therefore, there is a tremendous investment on the part of the health care professional in securing the patient's consent.

Outside the courtroom, surveys of patients and doctors indicate little consensus on what constitutes informed consent. Most of the physicians questioned about informed consent never talked about the hazards and risks of the procedures at all. And the patients with whom informed consent was discussed said such things as "It means letting the doctor do whatever was necessary, best, or what he saw fit to do" or "giving a person permission to kill you" (Kelley, 1983).

As health professionals, we should know that the better-informed patient who has been apprised fully of the information that is required, and has actually exercised his own decision making in the treatment, often comes out with better physical results than those patients for whom the decisions were made by the health care professional. A better-informed patient is almost always a better patient.

The patient's right to refuse treatment is protected by the courts just as much as this right to consent. After all, without the right to refuse, the right to consent is meaningless. We talked about Ms. Conroy, Mr. Bartling, and Ms. Foody. All three were patients that wanted to exercise the right to refuse treatment. For each it was certain that the refusal would result in death.

The problem with the incompetent patient is how the patient is going to exercise that right. The incompetent patient is very often comatose, totally unable to exercise his own rights. Thus the courts have examined and ruled out who will exercise that patient's right to decide, and on what basis. We speak here about autonomy, so we are not talking about the substitute decision-maker's deciding on the basis of what he would like, if he was the patient. Nor are we talking about the substitute decision-maker's deciding on the basis of what he thinks would be best for that patient; i.e., the "best interest" of the patient. The judgement the substitute decision maker will make must be the decision that the patient would make for herself if she were capable of making it today.

How do we know what decision that patient would make? Basically, there are three ways we can learn what the patient would have decided. One is a written expression of what the patient wants, a "living will". A living will is legal even in a state that does not have a living will statute, although in such circumstances it may not always be binding. But most patients do not have living wills. Then the courts have looked at any prior verbal expression by the patient. Has he had any discussions with his friends? With his family? With his co-workers? Has the person expressed absolutely, that he did not want to be kept alive by artificial means? Sometimes we have such testimony. It is not as probative as a written document, but very often in court we rely upon verbal expressions.

Suppose, however, there is no written or verbal expression. Then we are left with the patient's behavior. How did the patient live his life while he was alive? That was exactly the situation in Mrs. Conroy's case. Her nephew testified that until three years prior to that court decision, Mrs. Conroy had never visited a medical doctor. In fact, she shunned medical care and the medical profession. From this the court inferred that she probably would not want to be lying in a fetal position, kept alive by a nasal gavage tube. The court ruled that she does have the right to have the tube removed, based on substituted judgement (Conroy, 1985, note).

Sandra Foody, the 42 year old with multiple sclerosis, was also on a ventilator. Likewise, she had never discussed whether she would want to be kept alive by artificial life supports. But the courts looked at how she had lived during her illness over a period of twenty years. The court saw that her attempt to live life to its fullest did not in any way encompass a life on a respirator with no possibility of recovery. Her vigor for life was the basis for the substituted decision to terminate treatment.

These cases have been extremely difficult for the judges involved. The patients have died, but the cases lived on, even though we might say death made them "moot". The courts have looked at the importance of these cases, and have agreed to hear and decide them even after the patient's death. We often view the law as something very mechanical and cold. Yet those decisions themselves clearly demonstrate the judges' profound struggle in making these decisions.

> When we deal with questions such as the ones presented in this case, certain basic humility and sense of one's own limitations are appropriate...We know that mankind's understanding of the ultimate meaning of life, suffering and death is (and probably always will be) flawed and limited (Conroy, 1985, p.1235).

This judge knows that these are not simple decisions. Society cannot escape the choice process, however.

One of the most interesting legal developments in the right to refuse treatment has been the growing judicial acceptance of a constitutional basis or underpinning for this right in both competent and incompetent patients. There is no definitive decision by the United States Supreme Court on the matter yet; but there are a number of important state court decisions which have expressly found such a constitutional right.

The first case to find such a constitutional right was the well-known case of Karen Ann Quinlan, (Quinlan, 1976). Miss Quinlan was a young woman who, for reasons unknown even today, found herself in a chronic vegetative state without cognitive function. She was maintained on a respirator. Ultimately, her father petitioned the New Jersey courts for appointment as her guardian in order to end her treatment. The New Jersey Supreme Court found Karen Quinlan's Constitutional rights broad enough to encompass her decision to decline medical treatment under certain circumstances, in much the same way as they are broad enough to encompass a woman's decision to terminate pregnancy under certain circumstances. The court built on Roe v. Wade, (1973) which found a right of "privacy" or "liberty" to terminate a pregnancy. The same right of liberty or privacy was also contained in the New Jersey state constitution.

Subsequent to the Quinlan case in 1976, a number of other state courts have created a right to refuse treatment explicitly based upon federal or state constitutional bases. In the Saikewicz (1977) case, for example, involving a profoundly retarded man who was being asked to undergo chemotherapy, the Supreme Court of Massachusetts found the constitutional right of privacy is "an expression of the sanctity of individual free choice and self determination as fundamental constituents of life. The value of life as so perceived is lessened, not by a decision to refuse treatment, but by the failure to allow a human being the right of choice" (N.E. 2d at 426). There have been similar decisions from the Appellate Courts of Florida, Georgia, Ohio, and a number of other states (Barry, 1984; Leach, 1984).

This development of a constitutional right of choice flows from a number of U.S. Supreme Court cases dealing with issues of procreation, marital choice, contraception, child rearing, and other intimate decisions of mature life (Skinner, 1942; Loving, 1967; Griswold, 1965; and Meyer, 1923). These cases rest on the Equal Protection, Due Process, and other clauses of the U.S. Constitution. The state courts that have found a right of privacy and autonomy in decision making about refusal of treatment have created a more generalized right of choice with respect to certain important personal decisions. That right cannot be interfered with by the government in the absence of very specific and compelling reasons.

Why have courts accepted this type of generalized claim? There are several bases for this acceptance. One is the "pedigree", the legal precedent, for this type of case. Patients such as Ms. Quinlan, Ms. Conroy, and others have been able to associate their claims with a long line of legal decisions concerning intimate choices. The history of these cases favoring autonomy goes back at least to the 1890's and perhaps even earlier. The "pedigree" of this right thus unites the ostensible differences between nineteenth century conservative courts, the Warren Court of the 1950's and 60's as well as the Burger Court of the 1970's and 80's.

Beyond the legal precedents, these claims have intuitive rhetorical appeal, linked to a respectable Western intellectual tradition. They rest on the idea that the individual can rationally decide his own choices, the kind of idea that Immanuel Kant (1965) refers to as the "dignity of autonomous rational being". Interference with that type of choice is an affront to that "dignity". J.S.Mill in 1859 writes in an influential essay, that a person "cannot rightfully be compelled to do or forbear because it will be better for him to do so. Over himself, over his own body and mind, the individual is sovereign." These types of legal claims likewise draw upon the ideas represented in popular culture by movies like "Whose Life Is It Anyway?".

But no constitutional right is absolute, whether explicit constitutional rights like free speech and free exercise of religion, or these non-specific rights of privacy and autonomy. In a recent case in

California, doctors and distributors were indicted and convicted because they prescribed the use of amygdalin or Laetrile, a drug not approved by the California and federal agencies dealing with drug therapies. They were convicted of conspiracy to sell and prescribe unapproved drugs, although the drugs were intended only for the alleviation of cancer. The Supreme Court of California rejected their claim that the right of privacy encompassed the right of individuals to treatments not recognized by appropriate governmental agencies (People v. Privitera, 1979).

Another limit on this Constitutional right was found in the case of Elizabeth Bouvia (1983), a 26 year old competent victim of cerebral palsy with a life expectancy of 15 or 20 years. She was admitted to a public hospital where she asked to be allowed to starve herself to death. The hospital refused and began force feeding her. She sought an injunction to end the force feedings and to require the hospital to administer pain medications and other palliatives to her during her waning days. The court refused her request for an injunction, and upheld the hospital's claim. The court ruled that the effect upon the medical staff and other handicapped individuals overweighed her right to decide her life. Both the Laetrile and Bouvia cases are examples of the state's interests overcoming patient's rights in some instances.

Outside the constitutional area, there are now 35 states that have enacted living will, or "death with dignity" statutes, allowing the withholding or withdrawing of medical treatment in various circumstances. But this legislative action reflects only the existing law in many states, and in addition, the statutes are often so narrowly drawn as to be of little help in specific situations. In addition, the legislative process often creates a product which essentially provides immunity for the provider. In many instances, these are "doctor's rights" statutes and not "patient's rights" statutes. Such statutes, if they are to be effective, must explicity extend this right of autonomy and decision-making to terminal and non-terminal patients, both competent and non-competent. In addition they must allow reasonable substitute decision making, and provide explicit penalties against health care providers for non-compliance with the statute.

The above developments, as you well recognize, are not the end of the process for these legal and ethical issues in health care. The cases multiply and the issues proliferate every day. We will soon be confronted with questions revolving around the legitimacy of the sale of organs as organ transplantation becomes more common. We are already in the midst of questions involving the legality and propriety of surrogate parenting in a variety of contexts. But the respect for individual autonomy which the courts have found in these cases are ultimate human rights. They must be respected even where the health care provider has different beliefs and, in fact, holds a medical opinion contrary to that of the patient. In effect, the patient here has the right to be "wrong." The decisions are hard, as the case of Elizabeth Bouvia demonstrates, and there will be no hard and fast rule that takes care of all these cases. As Willard Galen, the psychiatrist observed, "You should have sleepless nights about these decisions." They are not meant to be easy. The challenge for us nurses, as health care providers, is to prepare ourselves and the nurses who practice in our institutions to grapple with these choices. Our task is to create competent technicians and questing minds, open to disciplines other than our own. To quest, and only to quest for humane and just solutions to these issues.

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Compassion, Technology and the Law

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Thank you for the opportunity to participate in the Sixth Annual Fall Workshop of the Midwest Alliance in Nursing. The theme of the meeting, "Healthcare Ethics: Dilemmas, Issues and Conflicts," is most appropriate for these troubled times.

We are in the midst of some of the most exciting challenges in the recorded history of mankind. The information explosion continues unabated. Scientific and technological advances proceed at an accelerated pace. Instantaneous, worldwide mass communication is commonplace. Transportation technology is taking us into out space. Society has responded with soaring expectations. It should be an era of unbounded optimism and yet, I fear we suffer from nagging anxiety about the future.

The good news is that we now know we are capable of providing more and more high quality medical care services. The bad news is that it may cost more than society feels it can afford. The dilemma is one of great capability and great expectations fueled by instant mass communication, but with finite resources making terribly difficult choices inevitable.

History of Medical Ethics: A Brief Review

Since antiquity, physicians and society have been concerned about the moral aspects of medical practice. Egyptian papyri (dating from about the 16th century B.C.) describe the methods for establishing diagnoses, making decisions about whether to treat, and what kind of therapy is appropriate. In that ancient society, as long as the physician followed the prescribed rules, he was not held responsible should the patient fail to survive. On the other hand, if he experimented and tried a new form of treatment and the patient died, the physician might also lose his life (American College of Physicians, 1984, pp. 127-137).

Hummurabi, one of the kings of Babylon, in 2,000 B.C. elaborated a Code of Laws for the governance of those who practiced medicine and surgery. Hammurabi's Code antedates by 500 years the Ten Commandments, brought down from Mount Sinai by Moses. The Code of Hammurabi established surgical fees according to the social status of the patient and prescribed punishment for poor technical performance. Egyptian and Babylonian societies established rules and sanctions to affect the activities of physicians and surgeons. Aesculapius, a legendary physician, was deified in the 5th century B.C. The priests of Aesculapius emphasized little science, but much of art and magic. They were obligated to care equally for rich and poor.

Hippocrates (460-377 B.C.) initiated the tradition of the scientific method in medicine through his careful observations of patients. He and his disciples developed the Hippocratic oath which stressed the individual nature of man and incorporated the strict moral code of the Pythagoreans. "The Hippocratic physician's responsibility to the individual patient was paramount; it was the beginning of the benign paternalism that has characterized much of Western medicine.

Hindu and Chinese mores, with a heritage of a thousand years, developed precepts akin to those of the Babylonians and the Greeks. Writing from 200 B.C. and 200 A.D. reveal that a physician should have... "mercy on the sick and pledge himself to relieve suffering among all classes. Aristocrat or commoner, poor or rich, aged or young, beautiful or ugly, enemy or friend, native or foreigner, and educated or uneducated, are all to be treated equally. He should look upon the misery of the patient as if it were his own" (American College of Physicians, 1984, pp. 263-274).

There was a long slumber period during the European Dark Ages and science did not revive until medieval times. In the 16th century, the Royal College of Physicians of London drew up a penal code for physicians. Later, the word, "penal" was changed to "ethical" to avoid the implication of criminal activity.

The American Medical Association was founded in 1847 and adopted, as its code of ethics, Thomas Percival's "Medical Ethics." In the 19th century, all of the codes, including that of the British Medical Association, stressed behavior and etiquette, although the 1957 revision of the American Medical Association's ethical code begins with a reference to a physician's responsibility to his patient: "...the principal objective of the medical profession is to render service to humanity with full respect to the dignity of man...rendering to each a full measure of service and devotion" (American College of Physicians, 1984, pp. 263-274).

The World Medical Organization adopted its declaration of Geneva in 1948. This document is essentially a revision of the Hippocratic oath that is administered to those entering the medical profession. Almost simultaneously, the Nuremberg Code and the Declaration of Helsinki were promulgated, calling for the voluntary consent of human research subjects.

The unique relationship between physician and patient is largely responsible for current attitudes as they relate to ethical behavior. For most medical professionals, the simple guiding principle is that you do what benefits your patient.

The Dilemma

Stated simply, the dilemma is: We are capable of providing more medical care services than society seems willing to afford.

It hardly seems necessary to recount some of the astounding advances in medicine and science in the last four decades. Smallpox, poliomyelitis, and many infectious diseases have been eradicated through immunization. Other infectious diseases have been controlled or effectively treated as a consequence of discovering an imposing array of antibacterial agents and antibiotics. Previously fatal malignancies are now being cured. Cancer of the testes and some of the childhood leukemias are examples of dread neoplastic diseases which are not being cured through modern medical science. The advances in surgical and diagnostic technology are mind-boggling. We routinely transplant organs, re-attach severed extremities, implant artificial joints, restore vision by lens implantation and even implant artificial hearts. Infant and maternal mortality rates have declined dramatically to reach an alltime low. We live longer and healthier than we ever did before.

It cannot be denied that health care costs have been rising faster than the general inflation rate for at least the past half century. That fact is increasingly decried by one prophet or another as a national crisis in which our "finite resources" are allegedly being consumed so rapidly that only extensive restructuring of our health care system can prevent calamity (Lukemeyer and Foy, 1984). There is increasing evidence that the public perceives health care costs as the main problem facing medicine today. Unfortunately, physicians do not share the public's perception.

Controlling medical care costs has been a major initiative of government and third-party payers for many years. Cutting these costs is now a major priority of government, third-party payers, and the business community. The escalating annual health care cost, the deepening national dept, an aging population, a sluggish economy, and the inflation rate of a few years ago have spawned the many programs aimed at reducing health care costs.

Examples include the growing use of deductibles and co-payments on health insurance policies and the increasing requirement for second opinions prior to elective surgery. For several years, there has been a dramatic and increasing emphasis on ambulatory care and surgery. Government, business and insurance carriers have initiated more stringent utilization review programs in association with prehospitalization certification. A revolutionary new prospective pricing system was introduced for the Medicare patient population two short years ago. Business- and government-sponsored alternative delivery systems for medical care have resulted in a proliferation of preferred provider organizations, health maintenance organizations and other prepaid medical care systems.

Hospital admissions have decreased significantly and there has been a surprising decrease in length of stay for hospitalized patients. My concern is that the emphasis on cost containment is assuming a prominence and a force that threatens some of the most vulnerable members of our society.

"The choices we face are clear and painful. The United States can suffer a continual increase in medical expenditures and in expenditures yielding benefits worth less than costs. Or it can impose effective limits. If it follows the second course, it will have to confront a long list of hard decisions on which discussions has not yet begun. Rationing will inevitably be painful prescription." This statement appears in the book, The Painful Prescription, Rationing Hospital Care, by Henry Aaron, Ph.D and Williams B. Schwartz, M.D. Professor Alexander Morgan Capron, one of the nation's leading scholar/teachers in the field of bioethics, has been quoted as saying "bioethics and bioeconomic issues go hand-in-hand. You can't talk about one without the other. Economics always involves ethical issues -- value questions."

There seems to be reasonalbe agreement that scientific and technological advances contribute most significantly to the escalating medical costs. Governor Richard D. Lamm of Colorado states: "There are two unbreakable rules of economics that pertain to health care: 1) each dollar spent on health care is a dollar that can't be spent on something else and 2) no set of expenditures can rise faster than the gross national product (GNP) forever." He continues, "The current dilemma in medical ethics is that science is inventing new devices and techniques faster than our economy can affors to buy them. Because we do not have infinite resources, we must begin making choices" (Lamm, 1985).

"Developments in medical ethics in the past year imply that an important shift is taking place. While once the critical controversy in medical ethics dealt with personal problem faced by patients or health professionals, the ethics of medicine must now be essentially social. The central and controversial issues involve complex social, political, and economic relationships and the increasingly lay involvement in medical-ethical decision-making." (Veatch, 1984) Governor Lamm (1985) certainly subscribes to the viewpoint of medical-social ethics. He has stated, "In some cases, professional ethics merely sanctify greed and sanctimoniously justify what clearly is anti-social."

There is a changing relationship of physician and patient occurring under the new competitive environment and under the regulatory influence of government, third-party payers and business that could radically alter the traditional cooperative spirit that formerly marked the delivery of medical care. I agree with Victor Fuchs who warned that the current changes in the delivery of health care "could hold the seeds of their own destruction." New problems of inadequate medical care, resulting from a erosion of traditional professional ethics and a loss of cooperation, dependence, and trust among physician and patients, seem imminent.

Selected Examples of Ethical Issues for the 80's

Society is showing an increasing interest in the costs of sustaining life and dying. Dying occurs at the earliest age in life, as well as in old age. In March 1983, the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research issues its report entitled, *Deciding to Forego Life-Sustaining treatment* (President's Commission, 1983). Morris B. Abram, MA, JD, LLD, in his transmittal letter to the President, pointed that "this subject was not part of our original legislative mandate but was added as a natural outgrowth of our studies on informed consent, the 'definition' of death, and access to health care and because it seemed to us to involve some of the most important and troubling ethical and legal questions in modern medicine." He continued, "Neither criminal nor civil law precludes health care practitioners or their patients and relatives from reaching ethically and medically appropriate decisions about when to engage in or to forego efforts to sustain the lives of dying patients."

Applying the findings of their earlier study on informed consent, the Commission concluded "that the authority of competent, informed patients to decide about their health care encompasses the decision to forego treatment and allow death to occur. We note, however, that all patients including those who reject various forms of life-support should recieve other appropriate medical care to preserve their dignity and minimize suffering to the greatest extent possible."

The Paul Brophy Case

The celebrated Paul Brophy case has been given national publicity. Mr. Brophy, a 48-year-old former emergency medical technician, suffered a ruptured cerebral aneurysm and underwent brain surgery in March 1983. Subsequently, he has remained comatose and exhibits only brain stem function. Nutrition and fluid administration have been accomplished through a surgically placed gastrostomy tube. After a year of turmoil, the family sought the counsel of a Jesuit priest. Ultimately, the family decided to request that the physician and hospital withhold "artificial feeding." The physician and hospital did not comply and the debate was raged in local courts since that time. It has attracted national attention. Here is a patient who, just prior to his terrible illness, had indicated that he would not wish to be kept alive by artificial means, but now is irreversibly comatose and the family wishes to withhold the artificial feeding. This is currently in the courts and brings into sharp focus the entire issue of foregoing treatment in the irreversibly comatose patient. Please note I did not say a dying or terminally ill patient.

Related to the Paul Brophy case have been the questions that have since come up regarding total parenteral nutrition (TPN). Hyperalimentation has hailed in the 1970's as a breakthrough in the treatment of many diseases ranging from short bowel syndrome to cancer. TPN has such therapeutic power that it can prolong the lives of patients whose medical conditions might otherwise seem hopeless. This technique has raised questions as to whether it should be used to keep patients alive when they might prefer to die, and when providing care that is becoming increasingly expensive with the passage of time. It is estimated that there may be 10,000 or more patients like Mr. Brophy in the United States who could be sustained either by gastrostomy feeding or by TPN.

Can we afford it? Should "artificial feedings" continue?

Transplantation and Implementation

There has been exciting progress in the successful transplantation of kidneys, livers, and hearts in recent years. There is great hope and expectation. This is tempered by the reality of an insufficient number of organs and the medical costs associated with some of the transplantation programs. It is estimated that the cost of the first year of care for a heart transplant recipient approximates $100,000. Because of limitations in the number of hearts available, it is speculated that only about one out of 5,000 potential candidates actually receives such therapy. On a national scale, heart transplantation is far less costly than coronary bypass surgery. It would seem that for the foreseeable future, heart transplantation will be limited primarily because of the scarcity of donor organs.

If the artificial heart program is proven to be medically feasible, it probably will be much more costly than cardiac transplantation in that the first year costs will average $165,000. Easy availability of artificial hearts would do away with long waiting periods, and patient selection, undoubtedly, would become much more liberal. The Congressional Office of Technology has estimated that 33,000 individuals each year under the age 65 would be considered candidates for a total artificial heart or a left ventricular assist device. Cost estimates are a whopping $5.5 billion per year (Thorup, 1985).

It seems appropriate to remind you, at this juncture, that the same technologic methods are commonly employed to "treat" brain dead organ donors as are used to sustain living patients in intensive care units and operating rooms. Maintaining and acquiring organs for transplantation frequently necessitates treating brain dead patients as though they were alive. Stuart J. Younger, MD, and associate point out that "little attention has been given to the disturbing effects of organ-retrieval surgery on staff members in the intensive care unit and operating room--the health professionals who are most involved. Underlying the disturbance felt by staff members are concerns that organ donors are not dead, despite a declaration of brain death, and that the organ recovery process itself is somehow disrespectful and may, indeed, kill the donor. By ignoring these concerns, we may unwittingly magnify societal resistance to wider participation in organ donation (Younger, et al., 1985).

Cost-Cutting Initiatives

For the last decade, there have been increasing pressures to contain medical care costs. It has been generally agreed that quality of care can be maintained while seeking to avoid unnecessary hospitalization and over-utilization of the health care system. In recent years, hospitals are frantically retooling to compete in this new competitive environment. The vocabulary of hospital administrators and trustees is rapidly becoming more business-like. Administrators are presidents and vice-presidents who are identifying hospital product lines for aggressive marketing.

Hospital admissions are down, length of stay has decreased and the per capita visits to physicians have been declining rapidly in recent years. An increasing number of physicians are opting for one or another form of "corporate" employment. There is, in my view, an erosion in the fundamental physician-patient relationship. My fear is that the new social ethics and the economic-based, decision-making orientation for medical care will progressively deny needed services to some of the most vulnerable members in our society. Availability and accessibility of medical care for the aged, underinsured, and poor is at risk.

Do we have in place an adequate early alert warning system that will show us when we have begun to deny needed medical services for individual patients? It is essential that this kind of information be available if we are to make rational decisions about the use of societal monies. Rationing of medical care should not be left to chance, nor based on emotion or fear. The health society and individuals must be followed, and if indicators show a decline from present levels, society may want to increase the amount it is willing to pay for medical care.

Who will be the advocate for the elderly, the infirm, the underinsured, and the sick poor? It is the physician and nurse who must deal with these patients and their families on a one-on-one basis.

Among the conclusions reached by the 1983 President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research were the following: "1) The voluntary choice of a competent and informed patient should determine whether life-sustaining therapy will be undertaken; 2) an appropriate surrogate, ordinarily a family member, should be named to make decisions for incompetent patients; 3) the idea of 'ethics committees' should be explored to provide for review and consultation in certain cases;and 4) health care institutions may justifiably restrict the availability of certin options in order to use limited resources more effectively or to enhance equity in allocating them."

Ethics Committee

According to the Judicial Council of the American Medical Association, (Fost, 1985) "ethics committees in health care institutions should be voluntary, educational, and advisory in purpose so as not to interfere with the primary responsibility and relationship between physicians and their patients. Generally, the function of the ethics committee is to consider and assist in resolving unusual, complicated ethical problems involving issues that affect the care and treatment of patients within the health care institution and concern those persons who are responsible for their care and treatment" (Fost and Crawford, 1985).

The size and composition of ethics committees vary appreciably. This probably relates to the size and complexity of the institutions in which they function. It is premature to attempt to assess the effectiveness of hospital ethics committees. They do seem to be increasing in number and playing a larger role in promoting ethically defense decisions. This is done largely through education, establishment of hospital policies, and consultation and reveiw.

Conclusion

In the years ahead there will be increasing pressures to cut medical care costs. There will be an aging population and an increasing number of health professionals. There will be increasing competition among health care providers and the economic incentives will lead to a "corporate-type" medical care system with physicians as employees.

Scientific and technologic advances will accelerate. The public's expectations will soar to new heights. If we fail, there will be a greater erosion in the physician-to-patient relationship.

Medical-social and medical-economic ethics will necessitate rationing of health care. In the new ethics I hope we do not abandon entirely what has been the physician's basic responsibility to his patient: First do no harm!

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Nursing Ethics: The Common Moral Problems

How Can Nursing Ethics be Taught in an Associate Degree Nursing Program?

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Our associate degree nursing program integrates moral philosophy into required nursing courses in the nursing curriculum. A nursing course in the first semester and one in the last semester each contain a module specifically designed for the teaching of nursing ethics. Each module is eight contact hours in length and is team taught by a philosopher and a nurse. In addition, each nursing course in the program has objectives which require the student to identify the values and virtues of a caring professional nurse and to recognize and attempt to resolve with reason and sensitivity those ethical issues which confront nurses.

The goal is to educate nurses who adopt a moral point of view and nurses who can make and defend moral judgements. The objectives are to:

1) foster a sensitivity to the ethical issues nurses do face.
2) develop basic skills in critical thinking.
3) promote the application of these critical thinking skills to the analysis and reasoned resolution of ethical conflicts in nursing practice.
4) develop the skill to articulating the rational justification for such judgements, and articulating the need for considered moral judgements.

The modules are an appropriate, even an essential, addition to the nursing program because they deepen and broaden the education of nurses through the study of moral principles, the use of critical analysis, and careful reasoning. Good nursing is impossible apart from a humanistic context and that a crucial part of that context should be created by the nursing education process itself. The study of ethics is essential because nurses constantly interact with other persons and because those interactions often involve ethical conflicts, complicated by the fact that nurses lack autonomy.

The integration of the nursing ethics module into existing courses makes the theory relevant to nursing practice in that the students draw from their own experiences in the clinical setting as well as from vicarious experiences. Students are assigned to keep a daily journal of their clinical experiences. We ask that each student follow a logical format to arrive at a considered moral judgement: 1) sort out the relevant facts; 2) identify the moral principle(s) involved; 3) discuss possible resolutions; 4) formulate arguments to support the resolutions; 5) anticipate objections to the arguments; 6) consider the risks involved; 7) select the best resolution; and 8) show why it is the best resolution. In this way, the student arrives at a considered moral judgement. Near the end of the module the student is asked to go back through the journal, select a specific occurrence, and write a paper on one or more moral rules that have been either violated or implemented.

One example of a journal entry went as follows: A six month old infant was admitted to the pediatric department of one of the local hospitals after a cardiac arrest at home. The infant was to be transferred via helicopter to a medical center as soon as possible. During the infant's stay on the pediatric unit, the nurses wanted to place him in telemetry for monitoring purposes. The hospital had six telemetry units. All six units were in use. The head nurse said she believed children should have priority for equipment because of their young age. The principle of justice comes into question in such a case. Who should have use of special equipment if there is not enough for all who need it? Students are first taught to investigate the pertinent facts of the case. What is the condition of the other patients on telemetry? What good will come to the baby if telemetry is used? What harm if it is not used? What harm to other patients if one is taken off the unit? How much pain or suffering is involved? The students then consider other moral principles that might be relevant to the case and consider what are possible resolutions. When the student considers the possible resolutions, she must be able to make arguments to support the resolutions and anticipate any objections to the arguments. The student then select the best resolution and justify why it is the best. The result--a considered moral judgement.

Such cases are used not only for the journal paper, but may come up in class discussion. For instance, when the topic was respect for persons or autonomy, a student recounted the following:

> An elderly woman in a nursing home requested to wear her pink dress. The student looked in every possible place for the dress but could not find it. The woman insisted on her pink dress. The student asked the charge nurse where else she could look. The charge nurse replied, "Oh, just put any dress on her, she won't know the difference." The judgement of the class was that her preference be respected even though she was institutionalized and even though her competence was called into question.

Another case demonstrates a choice between truth telling and justifiable paternalism. A student reported an instance of preoperative teaching for an 82 year old man about to have an abdominal perineal resection. In the course of teaching, the patient asked if he would be impotent after the procedure. The doctor had discussed the procedure with him, but apparently did not address this aspect of the procedure. After deliberation the class came to the consensus judgement that in this situation a nurse would have an obligation to see that such a patient receives an answer to his question.

It is not always a major moral concern with a patient or doctor that creates unrest for students or for nurses. Sometimes it is a questionable rule or policy of a department or hospital that is the source of the problem. One hospital has a rule in the newborn nursery that the babies could not be unwrapped when taken to their mothers for feeding. This led one student to inquire: "Whose baby is it any way?" Another hospital has a rule that only nurses, but not doctors, visitors, dietary or laboratory workers, must step in a pan of antiseptic solution before working in the obstetric department. Questionable rules--often inconsistent and difficult to follow--may create dilemmas for nurses. Such institutional rules, when carefully considered, may reveal violation of moral rules such as autonomy, beneficence or non-maleficence.

The study of nursing ethics prepares the nursing student early in her career as a nurse to confront morally troubling situations methodically, reasonably, and sensitively. The student must ask, "What is the problem?", and "What risks must I take in order to effect the resolution?" All too often the risk is not carefully considered. Must the nurse always put her job or her professional relationships at risk? If not always, when should she be willing to take the greatest of risks? Our aim is for the student to sort out moral and prudential factors in each case, locating first the ideal resolution--then, and only then, considering the potential risk.

On occasion the student will bring a moral problem to class that we, as instructors, have not fully thought through or discussed with one another. We may find ourselves in disagreement about the resolution. Or we may bring a case of our own about which we disagree. This also is a learning experience for the students. They can see that we have not reached moral certainty, that we too must search for reasoned resolution and follow the same process in order to reach a considered judgement.

Ethics can provide answers for hard cases, but not without a thorough examination of relevant facts and consideration of the principles, rules, and intuitions relevant to those facts. Class discussion and the writing of case analyses provide the student with the opportunity to test the instructor's belief in the students' capacity to reach principled resolutions to everyday moral conflicts. Experience has tended to confirm this belief.

We make no apology for making the task of learning for the nursing student more difficult. We want the student to be sufficiently troubled to investigate the dilemmas they face, yet we do not want them to be overwhelmed. Our students know we are there for them. We share an office hour for this purpose, as well as being available at other times during the day. The journal helps the student keep the incident and her feelings fresh so she can give a clear picture to us or the class. It also helps the student to reflect more carefully as she writes the case after it has happened.

We are finding that our students are more sensitive to moral issues and not so reluctant to bring such issues to the attention of the instructors in other nursing courses. In the two years we have focused on nursing ethics in our nursing program, we believe we have prepared and are preparing nurses who are more aware of the realities of nursing practice and moral conflicts nurses face. They are keenly aware that good patient care includes a moral concern for persons as autonomous beings with differing needs and values. Such students possess a justifiable confidence in their decision-making, are better able to articulate and defend their reasons for considered judgements through investigation, critical analysis, and principled reasoning. In a small way, this can begin to bring about an increase in the autonomy that is so lacking for nurses. Students who can think critically for themselves can be more assertive as nurses.

Nursing Ethics: The Common Moral Problems

Is Nursing Ethics Possible?

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We begin with the wonderously depressing complaint proffered by a disgruntled student after a particularly spirited discussion of a grave moral issue facing nurses. Depending upon our mood or upon how a class has gone, we interpret that complaint alternately as a sign of our failure or of our success in teaching nursing ethics. "I do not like this class," the disgruntled student said, "because I have already made up my mind on such matters, [and there comes the clincher] I don't appreciate your making me rethink them." This complaint, admittedly an extreme example, is troubling for those of us who believe it is both possible and appropriate to teach nursing ethics. Two factors are especially disturbing. First, it reminds us of the melancholy fact that, Socrates to the contrary, a student may actually prefer the unexamined to the examined life. Second, it suggests that responsible ethical inquiry in such a context must pick its way between opposing hazards: the paralysis of doubt, on the one hand; and the retreat from moral ambiguity into dogmatism, on the other. Can we, and if so how do we, promote the analysis and principled resolution of moral problems in health care without indoctrination?. If, as much loose talk about values would have it, moral values are matters of mere preference, then we cannot, since we would be able to make no critical distinction between what *is* preferred and what *is to be* preferred. We will argue that, on the contrary, starting with shared moral intuitions and common moral problems rather than with abstruse theory or bone-crushing dilemma, one can teach nursing ethics, given two necessary conditions: a) having students who are predisposed to adopt a moral point of view and b) having students who, with newly acquired critical thinking tools, can recognize that some reasons are better than others, and, hence, to be preferred over those other reasons.

Barbers and bartenders, so the legend goes, avoid the topics of politics and religion. No health care professional, however, can afford the luxury of silence on, or tactical indifference on social divisive matters of value in health care. Moral issues are inextricably bound up with biomedical issues generally, and the good nurse is not merely the technically competent nor the merely well meaning nurse. It does matter and matter profoundly what conclusions nurses reach and what actions nurses take on moral matters. Pursuing right conclusions and right or good choices leads inevitably to the logical and ontological problem of value. Philosophically considered, values are not simple preferences, but norms or ideals. While this view may conflict with some current talk about the locus of values, it does accord with common morality, as practiced and as preached.

Our deepest shared moral intuitions are that, as a rule, one should value kindness over cruelty, fairness over favoritism, tolerance over prejudice, and generosity over miserliness. Common morality, along with normative ethics, insists that a person who demonstrates, whether by word or deed, a prejudice toward a racial, ethnic, or religious group is not merely a person who acts upon a different opinion or preference but a person with a moral failing. Certainly, common morality alone cannot give us clear rules governing who should live when not all can; or what harsh sanctions, if any, should be meted out to those who commit acts of passive or active euthanasia. When, however, nurses classify compassion, loyalty, and truthfulness as virtues, they are saying more than that such qualities represent their preferences. Consider the judgment which would be called down upon a nurse who in her practice exhibited a preference for the contraries of those virtues. We might go so far as to say that one who announced such contrary preferences would be a proper object of suspicion, and a moral nurse would, in certain instances, be obliged to warn others of the former's preference for vices. Here common morality and normative ethics are one in treating values as norms or ideals. For those who would still argue that, in the classroom at least, the teacher should never impose *her* values, we would suggest reflection on a possible student who exhibits a preference for cheating and plagiarizing to honest effort. Academic communities are one in their insistence on the norm of honesty, while philosophical ethics concurs and adds the Kantian rule of moral consistency, where one has a duty not to make herself an exception to a rule required of others.

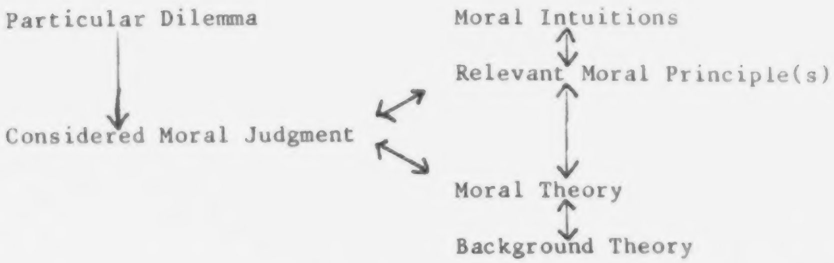
Ironically, it is the two most cherished values of democracy--freedom and tolerance--which, more than the philosophical problem of ethical relativism, give rise to the mistake over moral values. From those appropriately cherished values has emerged the principle of tolerance. Pluralistic societies allow for differing, even competing, conceptions of the good. It is often necessary to remind students, for instance, that health may not have the same priority among goods for the patient as for the nurse, thereby leading to questions of autonomy and paternalism. Yet there are acts which a tolerant society cannot and must not tolerate, and there are judgments and values which a tolerant society does and should condemn. Medical experiments performed upon unconsenting persons are wrong. Torture and killing of the materially innocent are wrong. Knowing that such acts are wrong, as a rule, if not absolutely wrong, takes but a moment's reflection upon our shared moral intuitions, our most cherished values, our broadest moral principles and major moral theories. It is, however, the hard case that is usually found to be the philosophically interesting and bone-crushing dilemma which holds the fickle attention of a sensationalizing mass media. When values, principles, intuition, and theories clash, we are drawn up short. There *is* reasonable disagreement about the kind of care morally required for the irreversibly unconscious, about the conditions rendering permissible or obligatory, the overriding of a patient's wishes, and about the fair allocation of scarce medical resources. Faced with problems where values and principles clash, we, as teachers, may wish to beg off, to stop after airing student opinion, examining empirical data, and clarifying values. But responsible teaching, we believe, must lead the student *in the* *direction* of a principled resolution to even the knottiest of moral issues. Beyond the classroom, a full conception of nursing ethics must include the *ideal* of a correct resolution to moral problems, however short of the ideal we may fall in our actual practices of moral reasoning. Moral problems generally, whether hard or easy cases, call for considered, rationally defensible judgments. The interesting or sensational case may not be the place to start with students, who first need to see why a moral consensus has grown around certain judgments and practices.

Figure 1. Ladder of Justification

Moral geometry
All-things-considered judgment
Most-things-rather-well-considered judgment
Common morality
Unreflective judgment
Mere preference

Ideals are not always realized or realizable, but they do provide us with standards for assessing our own desires, judgments, and actions. We can at least set up a ladder of goals moving toward the ideal and begin the climb. Picturing such a ladder, we would see at the top, following John Rawls (1971), a moral geometry. Starting from facts and true principles, we would ideally arrive at true resolutions by correct reasoning. A rung below is what Rawls himself, in his search for a full conception of justice as fairness, has spent a lifetime hoping and striving to achieve--reflective equilibrium, in other words, a stage where all of our moral intuitions, rules, principles, and theory, together with all relevant empirical facts and background theories logically cohere. After such an exhaustive examination, one arrives finally at the rung of an "all-things-considered judgment." While such a judgment may rest on a questionable premise somewhere, one will have achieved coherence, or in Rawlsian jargon: "equilibrium." Still an exhaustive search for coherence and truth cannot be the realistic goal of the nursing ethics classroom or even for most independent reflection on nursing ethics. Our rung must be a "most-things-rather-well-considered judgment." We can hope to reach an equilibrium of sorts, but only an uneasy one, subject to revision in the light of further research, after further reflection, or in response to significant but heretofore unconsidered objections. We are still far down the ladder from a Rawlsian ideal of a moral geometry, but far up the ladder from an unreflective judgment or mere preference. From our students we can at least demand a "some-things-considered-as-carefully-as can-be-expected judgment," one justified with a relevant intuition, rule, or principle, and, later in the course, possibly a theory as well, in addition to answering a possible objection.

Figure 2
Rawlsian Ideal of Reflective Equilibrium



Of course, each considered judgment requires a separate climb up the ladder of justification and in some cases the climb will be more arduous than others. Contrast, for example, a question about a nurse's proper role in withdrawing life-sustaining treatments with a problem like talking over the head of a patient as if the patient were not present. For the former we confront a large body of facts and predictions, as well as clashing principles and intuitions. Our best resolution may be quite tentative; in some cases we may have to defer judgment or seek the help of others. In the classroom we may be able to do no more than provide the student with a model of such reasoning which would hold only for certain hypothetical instances. When it comes to talking over the heads of patients, however, we can conclude with some justifiable confidence that, as a rule, such acts are wrong and that, in this context, nurses should develop the habit of speaking to or with patients and not about them, even where the patient's competence or consciousness is in question. The wrongness of such acts is clear from reflection on the respect due persons, the possible harm to therapy, and our own intuitions about how we would wish to be treated. Thus, whether the act arises from dispositional insensitivity, from momentary forgetfulness, or less plausibly, from faulty reasoning, it is, in our considered judgment, wrong. Arriving at this rung with students, we would not yet have a full account of why persons are entitled to respect, nor would we have a full theory of personal identity, so we would stop short of an "all-things-considered judgment." But such a judgment is more than a preference and is justified with more than a slogan.

Correctly understood and practiced then, the teaching of values in nursing ethics is the antithesis of indoctrination. If indoctrination means "to imbue a point of view, usually in a partisan or sectarian way," (Bowie, 1984), the critical task of determining which values and choices are justifiable cannot be indoctrination, since reason is the same everywhere. Indeed the mere airing of issues and points of view may contribute to indoctrination in that it may, however innocently, lead students to conclude that ethics involves simply choosing one doctrine over another. By starting with the analysis of settled judgments in less controversial cases, one can provide the student with a model of reasoning to apply in resolving harder cases, as well as demonstrate that in our common morality we do in fact treat considered judgments as norms or ideals. And, by stressing the incompleteness of our reflections and the room for error in our conclusions, we can enlist students in the common endeavor to climb the ladder of justification. Nurses, like all professionals and indeed all mortals, need to value and choose the right or best things and be capable of defending those values and choices before others. Failure to reach moral certainty need not result in the paralysis of doubt, and a measure of confidence in our considered judgments need not open one to the charge of dogmatism. As teachers of nursing ethics, we cannot and should not gaze down on hopeless students from the lofty heights of moral certainty. Rather our goal should be to convince them to join us in the arduous but essential climb up the ladder of justification in search of mutually considered moral judgments. The disgruntled student at the beginning of this paper stands before us both as a warning and as a challenge.

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Exclusion and Confirmation

A Phenomenology of Patients' Experiences with Caregivers

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The state of the art of health care is characterized by discontent and by increasing demands from consumers for compassionate care that preserves human dignity. Patients and their families are dissatisfied with the quality of human interaction found in the health care system. This discontent is reflected in popular literature such as Lear's (1980) "Heartsounds" and Cook's (1981) "Second Life", both written by individuals who present their experience with our technologically advanced, but dehumanizing system of care. Despite having the advantages of the latest scientific achievement, patients and their families are unhappy with the kind of care they receive. I believe this discontent comes from a sense of being an integer, without identity, in a system that has become a business enterprise. Patients dislike the fact that machines receive more attention from caregivers who ignore their presence while discussing them. They find it demeaning to undergo treatments or diagnostic procedures administered by caregivers who do not look at them or speak to them except to give instructions. They find it degrading to be left waiting for hours on a cart in a busy hallway outside an x-ray department, or to wait for hours without information about a delay in the surgery schedule. In view of this, should we not ask what is wrong with the way we provide care? Why is clinical competence not enough? And when is expertise hollow? Might not impersonal, albeit expert, care be as negligent as outright technical incompetence?

The Issue of Our Humanity

The issue of attending to our humanity in the face of increasing emphasis on technology in science has become a concern for scientists and philosophers during this century (Kuhn, 1970; Hanson, 1965; Lauden, 1977; Suppe, 1974; Husserl, 1962; Heidegger, 1962, 1977; Kohak, 1978; Gendlin, 1962). Husserl spoke of the danger of discounting lived experience and human subjectivity as false and relativistic. Those who discounted subjectivity, the positivists of the last century, were influential in the advancement of science. Positivism, belief in a set of immutable facts and an absolute truth, influenced not only scientific thinking, but extended to all of society as well. While it developed the scientific method as a rational, self-regulating process of learning, its approach to human experience was to see it as opaque as lived; becoming transparent and understandable only as observed, objectively, by disinterested or impartial scientists (Kohak, 1978). In other words, subjective experience was not to be trusted as a reliable way of knowing the world.

The danger of which Husserl spoke is that when the subjective is devalued or ignored, we can become removed from experience as it is lived, losing touch with feelings. Feelings are the source of understanding and eventual meaning, the source of creativity and the ability to conceptualize right and wrong. Feelings are our first approach to a situation or problem. We grasp something in a feeling/bodily sense before we identify and articulate it symbolically with language, equations, or art (Gendlin, 1962).

Although the distinction between subjective and objective has been useful for empirical science, the danger of maintaining the distinction in the health sciences is that subjective experience is dismissed as an inaccurate or irrelevant source of meaning and knowing and both caregivers and patients are removed from this vital area of understanding.

If we are to improve the quality of health care, to humanize it, we must begin to ask how patients understand their encounters with caregivers and then ground health care on their experiences of us. We need to learn not only which encounters are painful or distressing for them, but also which encounters are experienced as nurturing and confirming.

The Phenomenological Approach

Phenomenology has two components: phenomenon and logos. Phenomenon is derived from a Greek verb that means "to show itself." A phenomenon is something that can be brought to awareness; something that can be made visible, manifest. Logos, another Greek term, means "setting forth,"; "recounting"; "making a statement." Meaning is also part of logos, so that it can be understood as setting forth meaning. Phenomenology, therfore, is a setting forth of meaning of that which shows itself (Heidegger, 1962). More simply stated, it is a method of understanding the meaning of an event or an object.

Because phenomenology is a method of understanding, it is concerned with the way human consciousness sees things. That is, it is concerned not only with the thing being explored, but also with how the mind identifies it in the first place. Phenomenology is a science of the subjective, exploring consciousness and the objects of consciousness, but never in a reductionistic way. It does not separate subject and object, but rather, looks at the process of consciousness and the implicit subject-object relationship.

The rigor of phenomenology as a method of understanding is its refusal to accept a perception without first examining the influence of underlying beliefs naively held by the perceiver. Phenomenology refuses to ground investigations in unexamined beliefs, to start from a point of trust or reliance in the validity of a common sense understanding of the world. Husserl called this common sense understanding of the world the natural standpoint, depicting it as the everyday approach to reality in which experience is split into subjects and objects, the objects being attended to while the experiencing of them is overlooked.

The phenomenological approach begins at the moment of reflection when one stops to consider the meaning of an event or thing, and then to wonder about the act of reflecting itself. Kohak (1978) calls reflection the process of becoming aware of lived meaning. To be reflective about something, and furthermore, to be aware of the act of reflection, removes one from naive immersion in the world. The validity of statements and beliefs previously accepted as indicative of the real world are not longer taken for granted. This is not to say that the reality of the world is denied, nor the belief is replaced by disbelief, but that the beliefs that have heretofor guided one's action are temporarily suspended. In the moment of suspension and reflection an attitude of openness and awareness is adopted and one is capable of being surprised. Phenomenology then, becomes a matter of letting things speak for themselves. "To the things themselves" is the classic way of expressing concern with immediate experience; it was Husserl's exhortation to his followers.

The Significance of Phenomenological Research for the Health Sciences

In his essay "What is a Thing?" Heidegger (1967) maintained there is a need for rethinking about how we see things. Our approach to any question or problem is always already structured; we cannot approach what we want to study without already being involved with it. That we can see an event or object as something separate and distinct against other things means we have already approached it at some preconceptual level. Heidegger believes that our approach to a thing is to see it in space and time as a separate entity with its own location and at a particular point of time and that we do not question this approach. Such an approach to things has its history in the philosophies of rationalism and empiricism, that grew from the work of DeCartes. The two terms, rationalism and empiricism, reflect the split of intellect from experience that characterizes the scientific method. The salient point for health care professionals is that the thing-model of seeing and knowing separates what we encounter. Subject and object become split into "observer in here" and "thing out there." Feelings get divorced from situations and bodies from minds. To see another person as "body out there" is to represent the individual to ourselves as a thing. Representational thinking seeks to control, literally to represent something about which we can be certain.

Traditionally, the scientific method has tended to discount feelings, or personal experience, as an unreliable source of information. The scientists's own experience of a phenomenon being investigated, i.e., the way one approaches a problem in order to examine it, has not been considered an important aspect of research methodology in the physical sciences until recently (Kuhn, 1970; Hanson, 1965; Suppe, 1974). Because much of health care practice comes from the physical sciences, problems of illness/health are often approached in a reductionistic way that fragments patients into parts that are labeled biological, sociological, psychological components of a human being. Priority is given to the biological processes, the facts of health care, while the way patients experience being ill is ignored. The feelings involved in health care, both for patients as recipients of care, and for caregivers as scientists, are left unexplored as a source of information with which to plan the care to be given.

The phenomenological method brings research to fundamental questions about the human condition that the traditional scientific method has not addressed. For patients in the health care system these questions may revolve around having no control of one's own body; loss of self-confidence; being dependent on strangers for basic needs; needing human warmth and nurturing for health and healing; reacquaintance with awareness of one's own death and the accompanying assessment of what one has done with one's life: Will it have mattered that I lived? Is there meaning to my suffering? Phenomenology creates the forum for considering the issue of being human and what it means to both patients and caregivers. Phenomenologically oriented health care does not replace or negate objective, scientific care, but rather, grounds it in patients' experiences (Kestenbaum, 1982). The important and immediate information that phenomenology offers is the knowledge that patients have of themselves and upon which technological care can be based for more human health care.

Literature

One other author, Van den Berg (1955) depicts the phenomenon of depersonalization as exclusion from others: "When excluded we see ourselves and our bodies as undesirable, unwanted and we cannot inhabit our bodies easily and freely as we would when we feel accepted and confirmed by others. There grows a split between mind and body, we become embarrassed, ashamed, self-conscious" (p. 55).

Other literature supports the need for health care professionals to become aware of the ways patients interpret their experiences and manage themselves emotionally. However, neither the experience of exclusion, nor that of confirmation has been studied systematically in order to clarify the meanings patients ascribe to each.

There are health care professionals who recognize the healing and nurturing that compassionate behavior from caregivers brings to patients. Paterson and Zderad (1976) characterize humanistic nursing "as nurturing response from one person to another in need" which "aims at the development of human potential" (p. 14). Schmidt (1972) discusses the concept of availability in nursing practice and its effect on nurse/patient relationships. In an earlier article, Vailott (1966) espoused the philosophy of existentialism as a statement of commitment for nurses who believe that the patient's experience is the well-spring of practice theory. Roberts (1976, 1978) discusses the relationship between technology and depersonalization in health care and devotes a significant portion of the text to the ways nurses can personalize care. In their philosophic text, Paterson and Zderad present human subjective experience as a crucial focus for humanistic nursing practice.

Leininger (1977) equates humanistic nursing with the concept of caring, stating, "it is caring that is the most essential and critical ingredient to any curative process" (p. 2). Engel (1980) equates caring with confirmation and validation. She describes confirmation as "acceptance that the client knows how he feels" and uses the term disconfirmation to depict caregiver behavior that depersonalizes patients.

Spicker and Gadow (1980) acknowledge the need to humanize health care. They observe that technology and science have failed to give satisfactory results in the health care field because they are not balanced with sensitivity and responsiveness to human need (p. xxv). Supporting this theme, Kestenbaum (1982) calls for a restructuring of thinking in the health care sciences. He maintains that subjective experience is fundamentally important not because it is a subjective accounting of a pre-existing objective reality, but because lived experience is reality as given in a subject's experience (p. 14).

Studies that have investigated depersonalizing human interaction include Geller, et al., (1976) who examined the effect of being ignored. They found that when persons were ignored there were negative consequences in subsequent interpersonal relationships. Duff and Hollingsheads (1968) sociological study of patients, caregivers, and families, described the interactions between patients and caregivers as characterized by frequently brutal relationships, emotional distancing and unwillingness or inability to recognize anguish. Lynch (1977) discussed the effect of human relationship on the cardiovascular system and suggestd there is a strong probability of causal relationship between interpersonal rejection and myocardial infarction. As a result of experimental studies with rabbits, Cornhill, et al., (1980) link psychosocial disruption to pathological changes in the cardiovascular system. Their studies indicated that the establishment of a pet relationship (a one-to-one relationship with the experimenter in which the rabbits were held and fondled morning and night) dramatically reduced the effects of diet-induced atherosclerosis in rabbits.

Flaskerud, et al., (1979) described interactions between nurses and patients as "uninvolved and often dehumanizing." They state, "nursing today seems to be characterized by a distancing and avoidance relationship with the patient."

Communications studies have examined the interaction between caregivers and patients as well as the efficacy of empathy training for caregivers (Hardin and Halaris, 1983; Heineken, 1983; Blondis and Jackson, 1982; Layton, 1979; La Monica, et. al., 1975; Diers and Schmidt, 1977; Wallston and Wallston, 1975; Kalisch, 1971; Hays, 1966; Methven and Scholtfeldt, 1962; Meyers, 1964). However, these studies did not examine the process of encounter with caregivers as it is experienced by patients.

In summary, the literature acknowledges the need for humanistic, confirming interaction in health care. Studies have been devised to alleviate depersonalizing interaction by training caregivers to become aware of empathic communication techniques. But the studies have not examined the process of interaction phenomenologically from patients' perspectives.

Exclusion and Confirmation

In an earlier study (Anderson, 1981) the concept of exclusion was developed to indicate the depersonalization that arises from situations in which patients' feelings are disregarded by the caregivers upon whom they are dependent. In the present study exclusion was found to be an interpersonal process between patients and caregivers in which certain behaviors are perceived by patients as caregivers' negative regard to them, and to which patients respond both cognitively and affectively. The phenomenon of exclusion is in opposition to holistic health care. To feel excluded, that is, to experience one's feelings being disregarded by another upon whom one depends is to feel objectified by that person. Exclusion reflects the idea that mind, feelings, emotions and thought are separate from the body.

The present study also examined the opposite of exclusion, confirmation, which is conceived as having one's feelings acknowledged by the important other, to be a human presence to the other person. For patients it involves being another mind as well as body to caregivers. It, too, was found to be an interactional process between patients and caregivers.

Whereas exclusion may deplete energy needed for healing, confirmation seems to augment it and offset the dehumanizing qualities of technology, reintegrating feeling and intellect, mind and body. To be confirmed is to have one's existence acknowledged by another (Jourard, 1968). Jourard (1971) also states, about the effect of confirming behavior, that being heard and touched by another who cares seems to reinforce identity, mobilize spirit and promote self-healing (p. 87). He maintains that impersonal relationships with others bring about a state of vague depression in which one loses hope and becomes vulnerable to sickness (1971, p. 206).

The Study

The study was conducted on a surgical unit and an obstetrical/gynecological unit of a 374 bed community hospital. The study was undertaken to explore how situations and interactions that are experienced by patients as depersonalizing are given that meaning by them. At the same time, the intent was also to explore how patients define and respond to interactions that they view as personally confirming.

Subjects were chosen after preliminary screening by the charge nurse on each unit for those patients whom she thought were feeling well enough to be interviewed. Each potential subject was then approached and given an explanation of the project; they were asked if they would be willing to talk about their feelings about being a patient. Each person was given an information sheet that explained who the nurse researcher was and the intent of the study which was to explore what it means to patients to feel either confirmed or depersonalized by caregivers and what caregivers' behavior means to patients. Other information included the fact that the interview would be taped recorded and would be held in confidence. Thirteen men and twenty-two women ranging in age from 20 to 79 years, agreed to participate.

A schedule of interview questions was devised for the study and was evaluated by a group of health care professionals (a psychologist, a sociologist, and several nurses) for content validity, clarity, and simplicity. The first question, Can you describe one positive and one negative experience with a caregiver? was the principle inquiry of the interview guide. Subsequent questions probed for the subjects' feelings and responses to the remembered situations. Subjects were also asked, What is it about a caregiver that lets you feel like a person? Like a non-person? and, Do you think any of the feelings you have described affect your health or state of being in any way? As a way of checking for biasing of answers by questions asked of them, the subjects were always asked, Have any of the questions about your description implied your feelings some way you really don't? and, Are you satisfied with your answers? Although the interviews always began with the first question, subsequent questions were asked when appropriate during the interview.

Reliability and Validity

Subjects' accounts of their experiences were accepted as their own particular view of the world. Although reactive effect of an interviewer on a subject's response is traditionally thought to be a source of bias, in phenomenological research the recounting of past experience is regarded as reliable data insofar as it is an expression of the feelings, thoughts, and emotions involved in the phenomenon being described. Data produced from memories and recall is not collected with the intention of generalizing to a greater population, but rather to add to, to enhance the composite of universal human phenomena with which we understand lived experience.

Colaizzi (1978) suggests that the validity of phenomenological research be measured with its own aim as the standard. He maintains that phenomenological data are valid to the extent that the interview tapped the subject's experience of a phenomenon. Such data are not examined for accuracy, but are viewed within the content of the subjects' experience, as expressions of their singular view of the world.

Validity of the interviews was addressed with the questions described above as well as during the process of transcribing. Listening to each session provided an opportunity for continuous evaluation of interviewing technique. As a result, the pace of the interviews was slowed so that subjects could get in touch with feelings they were trying to describe. Listening to the taped recordings also allowed monitoring for consistent wording of questions for each interview.

To make subjects more comfortable in expressing feelings about caregivers who might be caring for them during the present hospitalization, privacy was insured for the interviews.

The Experience of Exclusion

After summarizing and organizing the coded data it became apparent that both phenomena, exclusion and confirmation, are processes of interaction that arise from caregiver behaviors and patients' perceptions of them. The first stage of this process is the presentation of behaviors by caregivers. In the case of exclusion, subjects described their caregivers as lacking emotional warmth. When they talked about these caregivers whom they experienced negatively, they used a variety of adjectives: starchy, cold, stiff, mechanical, indifferent, bored, impatient, irritated, flip, close-minded, mean, zombie, robot, superior, dead-pan, disinterested, dismissive, insensitive, and preoccupied. In a In a general sense, what the subjects described were caregivers whom they felt had not cared about them.

In addition to lack of emotional warmth, the subjects also described caregivers' insensitivity to circumstances. A young woman who had recently given birth described how she had been distressed by an ultrasound technician's disregard for her need for privacy while undressing plus his apparent oblivion of her discomfort during the procedure: "He puts some jelly on my stomach and he doesn't say it's going to be cold, he just dumps it on there and starts rubbing it in...there were some areas of my stomach that were tender and he didn't take into account what he was doing..you could see by the expression on my face that it was hurting..."

Inappropriate emotional responses from caregivers was distressing. A 69 year old surgical patient talked about a physician whom he felt had been indifferent to his problem. "He was very blunt and didn't seem to understand the situation and he always made a joke of everything."

Subjects were sensitive to caregivers' tone of voice, which they often mimicked to convey the quality that made them feel excluded. They usually lowered their voices, and spoke in short, rapid, phrases, keeping any inflection out of their voices. In addition, they described the facial expression of caregivers they had experienced as cold and impersonal as "dead pan," or "like a robot," meaning flat, emotionless. Subjects also mentioned fast movements and a hurrying pace as conveying negative regard for them. They said they felt rushed, as though they were just another job on the list of things to be done.

Lack of eye contact, the use of false endearments, or a too casual attitude were identified by subjects as behaviors they experienced as depersonalizing. A 67 year old woman said, "I had continual pain in the middle of my chest and had to sleep propped up. I told the doctor and he was very flip. He said, 'Oh, don't worry about it, you'll probably have that the rest of your life; you'll just have to watch your diet." Two years later the woman was diagnosed by another physician with hiatal hernia and cancer of the colon.

Another woman said it mattered to her where caregivers stood when talking with her. "Some nurses seem almost afraid to get close to me."

Subjects also deplored being "talked down to," having their questions dismissed as trivial, and being given information with medical terms or jargon they could not understand. The abruptness and seeming indifference of an obstetrician during an initial prenatal check up was distressing for a young woman. "He made me feel like the whole thing was so routine...I felt like I was just another one that came in and out the door during the day...He made me feel stupid...I had questions and he wasn't interested in answering them."

The energy expended by a caregiver to be emotionally warm with the subjects was directly related to the experience of exclusion. Diminished energy with which to engage them was seen by some subjects as lack of personality, which was usually translated to not being cared about by the caregiver.

The second stage of the interaction process was identification of this behavior as an indication of the caregiver's negative regard for the subject. The affective and cognitive response to the perceived negative regard was the third stage of the process. Subjects experienced fear, anger, and shame in response to the identified behaviors. Cognitively, their responses were traceable along one of two paths, depending upon how they evaluated themselves in regard to interaction with caregivers. If they experienced themselves as a bother to caregivers, "asking for more than I should," or stupid, insignificant, a "nobody," "out of place, and out of line," without adequate means of alleviating associated painful feelings, then exclusion occurred. If however, the subjects were able to cope with the negative affective response of anger, fear, or shame, and maintain self-esteem, exclusion did not occur.

The Experience of Confirmation

Confirmation proceeded along the same lines. As with exclusion, the first stage consisted of presenting caregiver behaviors. When subjects described their experiences of confirmation they indicated caregiver characteristics in which there was a sense of energy being expended on their behalf. They expressed this sense of energy in caregivers as "wanting to be there," "caring what happens," "liking their work," and "having personality." Descriptions of caregivers who "like their work," implied energy and enthusiasm. A woman described a nurse at the time of delivery: "She sounded so excited, she was literally yelling, 'come on, come!' she said to my husband, 'look this is the head crowning; come see this! want to see your baby?' you know, she was just as excited as he was."

"Caring what happened" was illustrated by a young woman's description of the physicians who had cared for her critically ill husband. "They would always take the time and say, 'let's go find a place to sit down.' I never felt rushed; I always felt like they had all the time in the world to explain to me...that's all they wanted, to make me understand what was going on, not that they would necessarily be able to cure everything, but that I would understand what was going on."

Subjects were aware if their caregivers looked at them during interaction. A woman described how she had struggled to communicate with a nurse during recovery from general anesthesia: "I could see in her eyes she wanted to understand what I was trying to say." Subjects also said that their positive experiences involved caregivers who smiled and joked with them. Another woman described a resident who supported her during a painful procedure. "That doctor that had a red moustache, in intensive care, well, he really stuck by my side. When they were stickin' needles in my stomach, I didn't even get upset, or even scared, you know...he was right by my side, holdin my hand...they were talking to me, trying to make me laugh...you can't laugh, but it's the thought that counts."

Caregivers who moved slowly when caring for the subjects and who were physically relaxed were experienced as warm and caring. Almost any action taken for subjects was seen as confirming if the caregiver was perceived as not being in a hurry. In addition to the rate of speed with which caregivers moved, the direction of movements was noticed by subjects. Phrases such as, "they bent over to talk to me," "she comes close and looks at you," "he sits down where I can see," "he leaned forward" indicated the importance of body language in the experience of confirmation.

Calm acceptance of, and matter-of-factness about messes was decribed with relief and gratitude by subjects. A young woman who had undergone an emergency Caesarean section talked about two young radiology technicians: "They were very patient with me...when I got off the table and they saw all this blood and stuff they didn't even look twice at it...it was a relief that they didn't look at it like, 'oh, gee, we've go to pick this up.'"

Subjects indicated that caregivers who liked their work were open about themselves and willing to share their lives with patients. A woman who was a surgical patient described feeling confirmed by a laboratory technician who had had the same surgery. "There's one phlebotomist from the lab who also had a splenectomy and I found that very encouraging to know that there are other people out there walking around...She's a terrible phlebotomist, I hate to see her coming, God, I've got so many holes where she couldn't draw samples, but personally, she's a person to me!"

Touch was also important because it conveyed information about caregivers as persons, particularly, their attitude about their work. One young man described a nurse who patted his arm with a firm touch while starting intravenous fluids. "She patted my arm like, 'it's OK, don't worry about this, it will be over in a minute.'"

Tone of voice was mentioned by subjects. A composite of desriptions revealed that a low, modulated, tone of voice that is animated and with clearly enunciated speech is often associated with caregivers experienced as emotionally warm.

The subsequent stages of the process of confirmation are less complicated than that of exclusion. In stage two, caregiver behaviors were identified as indicators of positive regard for the subjects. In stage three, subjects' responses again consisted of both an affective and a cognitive component. The affective responses were feelings of hope, comfort, confidence, assurance, and a sense of ease and relaxation. Similarly, the cognitive element of response was one of positive self-evaluation, in which subjects experienced themselves as maintaining their individuality despite the depersonalizing structure of the health care system. They saw themselves as competent decision makers, and as possessing the necessary strength to get well.

Effects of Exclusion and Confirmation

The subjects had thoughts about the effects of both exclusion and confirmation. Eleven of the subjects thought that feeling excluded by caregivers would have no effect on one's state of health and/or recovery from illness. The remainder of the subjects had varying thoughts about the effects of exclusion. Some thought that feeling excluded by caregivers could slow the process of recovery and leave a patient inclined to give up hope. Others said that feeling excluded adds stress and uses up energy that could be put into the healing process. Four of the subjects said that they had been afraid to ask questions of caregivers by whom they had felt excluded. A young woman said of a nurse, "I felt I couldn't ask her anything because she gave me the impression, 'everybody goes through this...you aren't the first one to have a baby and you're not the last'." Subjects said they sometimes withdrew and stopped talking to caregivers they experienced as cold and impersonal, not wanting to risk feeling excluded again. Another woman said she thought patients feel tense and off-balance and do not rest easily if feeling excluded. For one woman, however, exclusion provided motivation to "get out of here as soon as possible!"

Subjects who were able to cope with the affective component of the interactional process, i.e., to deal with the anger, fear, or shame experienced with caregivers they perceived as having negative regard for them, were able to escape exclusion. They accomplished this with one of four different means: 1) seeking social support from family, friends, and other caregivers; 2) deciding to overlook the interaction, e.g., excusing caregivers because of the burden of the job; 3) withdrawing from further interaction with caregivers; and 4) expressing anger either directly, or to a sympathetic other.

When subjects talked about the effects of confirmation they often used the words relaxed, confident, stronger, "He made me feel confidence in myself," said a young woman of a physician who had encouraged her during labor and delivery. Another woman said of her physician, "He made me feel stronger as a person...that I was more in control." Eight of the subjects felt that being able to relax was an important part of recovery and that confirmation enables one to "put some distance between you and your problems, and allows the body to be more in tune with healing a wound, or whatever it has to do," as a 27 year old man expressed it. Four subjects expressed the relationship between confirmation and recovery/healing as one in which some form of energy is received by patient from caregivers. A 24 year old woman who had given birth to her first child described the nurse who had supported and coached her during labor: "I needed her strength...when she was helping me she'd hold my hand; she told me to squeeze. She knew how it felt, and she'd was doing the things for me that I couldn't do emotionally."

In summary, both confirmation and exclusion were associated with strong feelings for the subjects. Caregiver behavior that was identified as impatient and disinterested generated feelings of shame, fear, and anger; subjects experienced themselves as insignificant and a bother to caregivers. They perceived their experiences of exclusion as energy depleting, leaving them less able to cope with stress. On the other hand, caregiver behavior identified as warm and nurturing produced feelings of comfort, strength, and relaxation; subjects experienced themselves as less alone and more able to handle adversity. Essentially, confirmation gave energy to subjects while exclusion took away that which could have been used for health and recovery.

A composite of excluding behaviors and characteristics depict caregivers who 1) had constricted affect that subjects interpreted as lacking emotional warmth and not caring about them; 2) had comportment that subjects perceived as being hurried and disliking their jobs; 3) avoided eye contact with them; 4) had a flat tone of voice, and abrupt manner of speaking; 5) used jargon or oversimplified language that was distancing; and 6) avoided proximity with them. A composite of behavior that subjects identified as confirming depict caregivers who 1) had an expansive range of affect; 2) had a relaxed, yet energetic comportment; 3) looked at them during interaction; 4) had a range of modulation in their tone of voice; 5) did not use jargon; and 6) came close to them when speaking.

Intervention

For patients who do not have adequate ways of dealing with the negative feelings that exclusion generates, intervention can be made at stage two where caregiver behaviors are identified. Ideally, this is where exclusion might be offset before the anger, shame, fear, and helplessness are engendered. A caregiver who is aware of the dynamics of exclusion can help patients to see the behaviors for what they are without being hurt by the painful feelings associated with them. In addition to providing social support by intervening in the process of exclusion, caregivers can include family members and friends in the patient's plan of care. They can emphasize to husbands, wives, parents, and children of patients the importance of their presence and teach them ways in which to provide emotional support for the sick person. Families can also be taught to recognize and anticipate the circumstances (such as waiting for long periods of time without information, or being examined by a group of physicians who talk among themselves) that have an increased potential for becoming experiences of depersonalization for patients and encourage the family to be supportive at these times.

For those persons who have means of coping with the negative feelings associated with exclusion, intervening may simply be in the form of follow-up care. Caregivers might check with patients whom they suspect may have experienced exclusion in some way recently, asking them to relate the experience and their feelings about it.

Caregivers need support too. Subjects' descriptions of their exclusion experiences depicted caregivers behaviors that are strikingly similar to those listed in the literature on stress associated with service professions. Any occupation that requires one to deal with many people by providing some type of service day after day, presents the risk of depleting emotional reserves. Such emotional exhaustion is currently referred to as burnout. It is a response to the chronic everyday emotional drain of working closely with people. Maslach (1982) believes that over time, one's tolerance for emotional stress erodes under a never ending onslaught of emotional tension, resulting in the symptoms of burnout: chronic tiredness, muscular tension, psychomatic illness, a sense of reduced personal accomplishment, decreased self-esteem, and a growing dislike of people. The effect of providers' burnout on others is an increased insensitivity to recipients' feelings.

The burden of providing care for others who place their lives in caregivers' hands and expect their expertise to be always accompanied by compassion, patience, and commitment, day after day, may be too great for caregivers who do not have adequate social support either at work or at home. Humanizing health care cannot be meant for patients only, but for caregivers too. More attention can be given to the emotional needs of caregivers so that they in turn will have the emotional reserves with which to provide patients with confirming care.

Conclusion

A first step toward the humanization of health care is the explication of patients' experiences with caregivers and the meanings patients attribute to their encounters with them. Paterson and Zderad (1976) describe health care that unifies subjective experience with scientific objectivity as:

> a nurturing response of one person to another in need, aiming at the development of human potential...As something that happens between people, it reflects all the human potential and limitations of the person involved. As an intersubjective transaction, it holds the possibility for both persons to effect and be effected, the posibility for both to become more (p.14).

Apart from all of the complexities of a scientifically and technologically advanced system of care, the essence of health care is still "something that happens between people." Cultivation of this primordial relationship is necessary in order that the care does not diminish, but rather, nourishes the humanness of both giver and receiver.

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Health Professional's Obligation To Non-Compliant Patient

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One of the findings which emerged from a phenomenological study of patient compliance was that from the subjects' perspective health professionals have very limited responsibility to non-compliant clients. The subjects in this study were selected from a group of hypertensive clients who utilize the Nursing Center for Family Health at the School of Nursing, Purdue University for blood pressure monitoring and health counseling. The majority of the subjects had been diagnosed as having hypertension for 10 years or longer and most had moved into some degree of self-management. This mode of self-management is compatible with the subjects' belief that they bear the primary responsibility for managing their hypertension, and that they are autonomous/self-determining individuals.

There are strong philosophical and legal grounds underlying the concept of client autonomy. Kant and Mill have provided the philosophical basis for understanding of autonomy. For Kant (1949), individual autonomy is a necessary condition for morality. Autonomy is governing oneself, including making one's own choices in accord with moral principles which are one's own and which are universalizable. Autonomy then for Kant is bound up with the concept of persons having unconditional worth; that is, persons are ends in themselves, determining their own destiny and are not to be treated merely as ends.

John Stewart Mill values autonomy for much different reasons. Mill (1974) argues that a society which fosters respect for persons as autonomous agents will be more progressive and on balance a happier society because its citizens will have the opportunity to develop their capacities to act as rational, responsible moral agents. For Mill to respect autonomous agents is to acknowledge their right to their own view and rightness of their actions based on such beliefs.

Aside from the philosophical basis for autonomy, there is now a growing legal basis for the concept of patient autonomy in one of the landmark cases, Canterbury v. Spence (1972). The recognition of the right to self-determination means that the patient has "an opportunity to evaluate knowledgeably the options available and the risks dependent upon each." Judge Robinson who rendered the decision in this case argues that physicians have a duty to satisfy the needs of the patient for adequate information. Competent adults have a right to decide for themselves what will be done to them, and have a right to receive adequate information to make these choices.

An even stronger view of this sort is found in Natanson v. Kline (1960). Justice Schroeder wrote, "Anglo-American Law starts with the premise of thorough-going self-determination. It follows that each man is considered to be master of his own body, and he may, if he be of sound mind, expressly prohibit the performance of life saving surgery." Although these cases involve the issue of informed consent, the principle being upheld is that of the patient's autonomy. Thus it would seem the arguments could logically be extended to the case of the non-compliant patient.

Because the clients' view that as autonomous adults they are responsible for managing their hypertension, they were asked what they saw as the health professionals' responsibility to patients who have hypertension. They were in total agreement that the health professional's responsibility lies in providing adequate information to the patients so the patients can decide what they are going to do. The subjects all recognized the health professional as the expert in health matters and thought patients should follow the expert's advice. But they all stated that the choice was ultimately that of induradal.

The recent report of the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research (1982) came to the same conclusion. The report asserts that the basic reason to honor an individual's choice about health care is that under most circulstances the outcomes that will best promote the person's well-being rests on a subjective judgement made by the individual.

If the health professional's responsibility to clients consists of informing and advising the individual, what is the health professional's responsibility to non-compliant patients? If patients elect to ignore the information or advice given by the health professional, is their responsibility any different from that of a car owner who seeks the advice of an auto mechanic who recommends that certain work be done, and then the owner ignores the advice? If the auto breaks down is the auto mechanic held responsible when the car owner, as an autonomous person, makes a decision not to follow the advice? The answer from the subjects was a resounding "no". Subjects do not see any difference in the relationship between a health professional and a client, and an auto mechanic and a care owner.

They prefer a contractual model of health care which is complimentary to their beliefs that they are responsible for managing their hypertension. From the subjects' perspective, the health professional has discharged his or her responsibilities when he or she has explained the consequences of the person's actions. Several of the subjects expressed surprise that health professionals would assume such responsibility. One subject responded "Why in the world would any doctor or nurse think they were responsible for what another adult does?"

The philosophical and legal requirements of respect for the autonomy of patients has given rise to several specific rights - among them the right to participate in treatment decisions, the right of informed consent, and the right to refuse treatment. Ackerman (1982) points out that this notion of respect for autonomy makes noninterference its necessary condition. An argument could be made for the position that the right to be noncompliant is merely an extension of the right to refuse treatment.

Or perhaps there is another right, the right to be unhealthy and this might include the right to be noncompliant. If there were such rights, what would be the obligations of health professionals to clients who choose to exercise these rights? How far does the client's autonomy extend? Is autonomy a prima facie right or is it an absolute right? Prima facie rights are always binding unless they conflict with stronger rights.

If autonomy in health is to be understood as an absolute right, like the right of free speech, it must be understood that it is the patient's right to exercise it. No one is under any obligation to respect a right the patient chooses to waive or for any reason not to assert. Pellegrino (1975) reminds us that there must be a balance between the client's right to autonomy and the health professional's responsibility and obligation to promote the client's health. Some have argued that the client's right to be autonomy ends where the health professional's right to autonomy begins.

Shuman (1976), writing in the Wayne Law Review, presents an interesting argument for the right to be unhealthy which could be extended to the right to be noncompliant. He examines theories about what is normal or healthy and points out the circularity in the theories. The theories presume that what is normal or healthy is the norm and the norm is therefore to be normal and healthy. Historically, from the time of the Greeks, there has been social pressure to be healthy, and it is only recently that society has become somewhat more tolerant of those who hold different values of what health is. Shuman summarizes the arguments for rejecting or severely limiting the right to be unhealthy.

1. When a disabling anatomical or physiochemical dysfunction is identified, proper function should be restored if possible.

2. No rational person would choose to be unnecessarily disabled by a correctable dysfunction.

3. Therefore, anyone who chooses to be unhealthy when the dysfunction can be corrected is abnormal and lacks the minimum qualifications for exercising the right to be unhealthy.

Shuman then continued and described two positions in support of the right to be unhealthy; the first he calls the health anarchist. This person would argue that the right to be unhealthy, once established, like the right of free speech, is absolute. There are no overriding rights. The individual must never be forced to undergo an unwanted medical treatment even if such a regimen would make him healthier or prevent harm to others. In other words, to respect the individual's autonomy requires noninterference on the part of others. The patient's right to autonomy would override the health professional's responsibility to promote health. This conclusion has its philosophical roots in Kant, whose respect for automony flows from the recognition that all persons have unconditional worth and therefore have the right to determine their own destiny. This veiw of autonomy amounts to a moral imperative. If health professionals accept this position they would have an obligation not to interfere. They would have an obligation to respect the individual's right to be unhealthy.

For the health anarchist autonomy is such a supreme value that it is inconsistent with any form of authority which attempts to make decisions about the lives of autonomous individuals. This radical position would reject the legitimacy of medical authorities ever intervening in the lives of autonomous persons even if the intervention would save the persons' lives.

Those who oppose the position that autonomy is an absolute right point out that if the patient dies as a result of the health professionals' noninterference, the person has lost all claim of his right of autonomy. When respect for autonomy is understood as noninterference, the health professional's role is dramatically simplified. He or she need only be an honest and skilled technician who provides relevant information and practices professionally competent care. Ackerman (1982) contends that noninterference really does not respect the patient's autonomy because it fails to recognize the effect of disease and illness on autonomy. Newton (1981) writes that the patient's autonomy is the first casualty in the ontological onslaught patients are caught up in when they enter the health care system.

The second position which Shuman describes is that of the health liberal. This person equates "good" with good health and would argue that the right to be unhealthy is a prima facie right and as such does not warrant the individual refusing intervention that would make him better or prevent harm to others. Mill's views on individualism and social liberty support a more limited concept of autonomy than that found in Kant. Mill would more likely align himself with the health liberal. For Mill an agent should be free to perform whatever action he or she wishes, even if that action involves serious risks, and even if others consider the act foolish, insofar as the agent's actions do not infringe on the autonomous actions of others.

One part of the argument hinges on the concept that the intervention proposed would make the person better. Since the case for showing that any medical regime does more good than harm and thus would make the person better is very difficult to argue, the health liberal would turn to the argument for preventing harm to others as the only grounds for intervening. John Stuart Mill's "one very simple principle" would be the basis for the health liberals' position, "that the sole end for which mankind is warranted in interfering with the liberty of action of any of their number is self-protection...his own good, either physical or moral, is not sufficient warrant". The health professional could justify overriding the patient's right to autonomy by demonstrating that the patient's noncompliant behavior would harm others perhaps depriving his family of a father and husband or on the basis of the costs to society of caring for the person when his health has deteriorated. The health professional could also show the harm that would be suffered if he was forced to abandon his responsibility to promote the person's health in order to allow the patient to be autonomous. This could result in moral or economic suffering for the health professional. These arguments all have a paternalistic sound which many find offensive in contemporary society, and yet few health professionals would be comfortable with the position of the health anarchists; so, most of us must find a middle ground. Most health professionals believe they have a responsibility to see that patients do what is best for them, and many feel guilty when the patients do not follow medical advice.

Although most of the authors cited in this paper use the generic term health professionals it seems they are implicity speaking about physicians. What about nursing? What obligations do nurses have to noncompliant clients?

Curtin (1979) describes nursing as a moral act whose purpose is the welfare of other human beings. She contends that this end is not a scientific end, but rather a moral one as it involves the seeking of good. Nursing is a moral act because it involves other human beings, nursing's relationships with those human beings, and the promotion of what we see as mutual "good", i.e., the person's health. Curtin proposes that the philosophical foundation for the most appropriate model of nursing is that of advocate. In this model of nursing the responsibility of nurses is to maintain the patient's autonomy. Nurses can do this by creating an environment that is open and supportive of the individual's decision making. Curtin points out that we often get caught up in the policies and procedures of the institutions in which we practice nursing and we may overlook minor infractions of the individual's autonomy. An example is the nurse who comes into the patient's room and starts an I.V. without explanation to the patient of what the I.V. is, or what it is for. Each individual violation may or may not amount to a serious infringement of the patient's autonomy, but collectively they constitute both physical and psychological attack on the patient's autonomy.

Muyskens (1982) writes that the nurse's role is at its fundamental level a moral one, one of ensuring the dignity and autonomy of the client in need. Like Curtin he bases this on a conception that the ideal model for achieving the primary objectives of nursing is that of client advocate. This model rests on the Kantian principles of respect for autonomy. Muyskens urges that the duty to protect the client's right to self-determination takes priority over the duty to promote the client's best interest.

So we have a dilemma. Is nursing primarily concerned with promoting the client's best interest or with protecting the client's right to autonomy, the right to choose? Obviously we would like to do both, but when both cannot be done we are forced to make a choice. I think most nurses would opt for doing what is in the best interest of the client rather than respecting the individual's wants. Yet if we are going to be consistent with the moral position that nursing's fundamental role is protecting the client's autonomy, we must maintain that the duty to protect the client's right to autonomy, the right to choose, takes priority over that of promoting his or her best interests.

The ANA Code for Nurses (1976) spells out that respect for human dignity requires that we recognize and support the patient's/client's right to self determination as an intergral part of nursing. So as Kant, Curtin, Muyskens and others have reminded us, it is because of this respect for human dignity that we must support the patient's right to autonomy.

The principle of autonomy sees man as capable of assuming responsibility for himself. Overriding the patient's right to be autonomous would require a very strong case. As Engelhardt so succinctly put it:

> In short, one must be willing, as a price for recognizing the freedom of others, to live with the consequences of that freedom, some persons will make choices that they may regret were they to live longer. But humans are not only free beings, they are temporal beings, and the freedom that is actual is that of the present. Competent adults should be allowed to make tragic decisions, if nowhere else, at least concerning what quality of life they wish for themselves. It is not the health care professionals' responsibility to prevent tragedies by denying autonomy, for what would be the greater tragedy (p.47).

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Criteria for ethical evaluation of Nursing Diagnosis

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At the present time there is a national effort to identify, standardize and classify health problems treated by nurses. It began with the 1973 National Conference on the Classification of Nursing Diagnoses. In many states nursing diagnosis is a legally defined aspect of practice. According to Marjory Gordon the assumption that we all must make is that nursing diagnosis is an integral part of the nursing process.

Nursing diagnosis is defined as the "description of actual or potential health problems which nurses by virtue of their education, are capable and licensed to treat" (Gordon, 1982, p. 2). Thus not only is a nursing diagnosis the description of an "existing deviation from health", but also any potential problem which nursing care might prevent (Gordon, 1982, p. 3).

Medical diagnosis by nature of its subject matter - disease - is primarily objective and deals with signs and symptoms. Nursing diagnosis by its very nature, however, deals with subjective value laden "health problems". Thus the purpose of this article is to point out some of the ethical questions inherent in making a nursing diagnosis and to suggest possible ethical criteria for evaluating nursing diagnoses.

First, the term "health" may have various interpretations and definitions. The meaning of health to one person may not be health to another. To some persons loss of health means feeling ill, to others exhibiting signs of symptoms, and to others still, the inability to perform duties or responsibilities.

Second, nursing diagnoses contain many value laden terms such as "dysfunctional", "impaired", "ineffective", "deficit" or "noncompliance". Here, too, impairement or dysfunction may mean different things to different people. Noncompliance to one person may mean survival to another.

These issues are not raised to discredit nursing diagnoses, but rather to express concern about their future development. The psychiatric branch of medicine and medical sociologists have grappled with similar concerns for years. The possibility exists that nursing diagnosis could become simply a labeling process, rather than a basis for determining appropriate nursing services for clients.

With this in mind, ethical criteria are presented for evaluating nursing diagnosis.

1) Is the definition of health assumed within the nursing diagnosis universalistic? That is, can the definition of health be applied to all

clients regardless of culture, race, creed or sex? For example, nursing diagnosis frequently pertains to psychosocial "problems". In this area definitions of psychological or social health vary widely across cultures. For example, Indian and Black indicators of health are not the same as Caucasian indicators of health. If an Italian mother's child dies, the mother may continue for months to sob uncontrollably over the child's death; while a mother of Irish descent who loses her child may not shed a tear, but continues to care for her family, and yet may frequently sit quietly by herself in deep thought. Which of these mothers is demonstrating "dysfunctional grieving", or are both within normal psychological range of their respective cultures? And who decides whether they are or not?

2) Is the practitioner's belief about the client's "state of health" congruent with the client's perceived state of health? And if not, which standard of health should be used? For example, a client has hypertension and is taking Aidoment 250 mg Tid. Over the course of several months the client has become impotent and depressed and without consultation stopped taking the medication. Without the medication the client feels "healthy". With the medication the client feels depressed. Should the diagnosis be "noncompliance"? Another client is taking Propanolol 40 mg Qid for angina, but begins to feel nauseated and stops the medication preferring to live with the infrequent angina. Again, should the diagnosis be "noncompliance?" Or is this merely a difference in the perception of "health"?

3) Does the nursing diagnosis protect the client's "personhood"? For this criteria we might use an adaptation of Fletcher's definition of personhood (Fletcher, 1972, 52-57). We could ask - Does the nursing diagnosis build on the client's intelligence? Does it promote self awareness and self control? Does the nursing diagnosis promote the client's ability to relate to others or if the diagnosis were revealed would it hamper the client's relationships with others? Does the diagnosis facilitate the client's communication? Does it allow the client more control over his or her existence?

For example, think of the diagnosis "coping, ineffective individual". A twenty-four year old white male, married with one child comes into a clinic and confesses that he becomes so angry with the crying of his infant son that he has to leave the house for fear of exploding. The nurse makes a diagnosis of "coping, ineffective individual". In and of itself this diagnosis is probably correct, but the use of diagnosis is another matter. We as practitioners need to use the diagnosis to promote this person's self awareness, his self control, ability to relate to his family, communication and control over his own existence.

4) Does the nursing diagnosis and its use maintain the clients autonomy or is it paternalistic?

Autonomy is defined here as a form of personal liberty of action in which the individual determines his or her own course of action in accordance with a plan chosen by himself or herself. A person's autonomy is his or her independence, self reliance and self contained ability to decide (Beauchamp, 1979, p. 56).

Paternalism refers to the belief that as a father figure a professional knows what is best for the client under certain circumstances. Any "potential" nursing diagnosis also contains the potential for paternalism, by virtue of the fact that a professional may see a problem which the client may not see; for example "knowledge deficit". Anytime the client's health related knowledge appears deficient, the care giver is inclined to tell the client what he or she (the professional) thinks the client should know. The following example illustrates this point. A young woman enters a clinic for birth control information and the nurse practitioner decides from what the client says that she has a "knowledge deficit". After discussing the methods of birth control the nurse practitioner decides that an IUD is the preferred method of birth control. She doesn't mention to the young woman that the IUD is an abortifacient. And the young woman who really does have a "knowledge deficit" agrees, but agrees because of imperfect knowledge.

5) In using nursing diagnosis, do we protect and insure the client's right to informed consent, truth, and confidentiality? If the nurse has a client whose diagnosis is "alterations in thought processes", she may not be reimbursed through insurance for the care of this client unless the diagnosis is revealed to the third party payer. In a situation like this, how does the nurse protect the client's rights to confidentiality? Or to informed consent as to how the diagnosis will be used? How can the client's right to the truth be protected? And how can the nurse explain the diagnosis to the client - its signs, symptoms and treatment?

6) Does the nursing diagnosis promote beneficence and avoid maleficence? That is, will the diagnosis promote "good" and "do no harm"? Using the above example again, will a diagnosis of "alterations in thought processes" benefit the client or will the diagnosis merely stigmatize the client? Do we ever know what an alteration in thought process is? Can we quantify and treat it? We need to be very clear about whether we are serving our own interests or those of the clients. It is possible that the client will be relieved to have a name applied to his or her discomfort. Yet, we still have to consider the possible negative effect of labelling.

7) Is the practice of nursing diagnosis just? According to Rawls, (1958, p. 170), "A practice will strike the parties as fair if none feels that by participating in it, they or any of the others are taken advantage of, or forced to give in to claims, which they do not regard as legitimate". Nurses generally believe that clients should be involved in their own care. Few would disagree that clients should also be involved in the diagnostic process. A diagnosis, "self-care deficit", for example, may result from the nurse's assessment of the client's activities of daily living. The client is more likely to see nursing diagnosis and care as just if he or she has an active role in the determination of the

deficits that actually exist. Using a specific example, an 80 year old woman is having difficulty feeding herself. In order for the practitioner's diagnosis to be seen as fair or just the client must recognize that she has a problem in feeding herself. A positive aspect of nursing diagnosis could be that to ensure justice, the client will be required to have more involvement in his/her care. In fact, many nursing diagnoses incorporate client involvement.

Justice in nursing diagnosis is also exemplified in the diagnosis "home maintenance management, impaired". A public health nurse sent to evaluate the home setting for social services finds that the client is unable to manage his/or her home. In order to be just, is the nurse responsible to social services or the client? How might the client be included in making the diagnosis? What implications does the diagnosis have for this client's future? Practitioners in the mental heatlh field have faced this dilemma for years. To whom are practitioners responsible - society or the client? What is the just decision?

8) Does the diagnosis protect the client's rights and fulfill our obligation? Consider the diagnoses - "injury, potential for" or "violence, potential for". Rights are usually classified as positive or negative. Our clients may have positive rights which means we have an obligation to do something or they may have negative rights which means we as practitioners have the obligation to refrain from doing something. For example, using the diagnoses above, if a small child has the positive right not be be potentially injured by an abusive parent then we as practitioners must accurately diagnose the potential for injury. Or looking at the opposite point of view the parents may have a negative right not to be falsely accused. Then we as practitioners have the obligation to refrain from making the diagnosis of potential injury. The same is true of the potential for violence. Society has the positive right to protection from potentially violent behavior, but the client may have the negative right of not being falsely or inaccurately labelled. Thus we need to be aware that diagnoses carry the responsibility for accuracy.

Eight criteria have been outlined for consideration when evaluating nursing diagnosis in an ethical context. There is danger that a nurse's well-intentioned diagnoses may result in some negative effects as an unintended or indirect consequence. Nurses who are developing nursing diagnoses as well as those using them must consider the ethical implications not only of the diagnostic categories and labels, but also of the potential side-effects of the process itself.

Diagnoses promote communication among health professionals, and help to standardize treatment to some extent; but most importantly, they should benefit the client.

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Nurse Advocacy for Client Autonomy: Resolving a Dilemma

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Noncompliance is a term frequently used to describe client behavior which does not conform to a prescribed regimen of care. When a client chooses not to participate in treatment, the client may be labeled 'non-compliant' by health care professionals. However, for the nurse who views clients as autonomous, the term may not be applicable.

In the home setting, the focus of considerable attention in recent years, the nurse faces the autonomy issue away from the brick-and-mortar policy realm of the institution. Policies are in place for delivery of safe care in the home, but the client's house rules usually hold precedence. "Compliance" with a prescribed care regimen takes on added dimensions in this setting. A case example is presented as follows:

> As the home care nurse in the low socio-economic, multi-racial section of town, I was assigned to George: forty-eight, six feet tall and weighing over 380 pounds. I was to "evaluate and treat the stasis ulcers on his legs, promote personal hygiene and work with him and his wife on weight reduction." I was told that George was "unemployed, on SSI; had questionable ability to follow through on instructions; a diabetic wife; and a mentally retarded son - 27". As I read the familiar pink referral form, I felt a combination of optimism and doubt. George might be more teachable in his own surroundings. However, he could choose not to follow the prescribed medical regimen and not to change his eating and hygiene practices.
>
> I parked my yellow Toyota in front of a tar-paper shanty. On the sagging front porch spread the largest single human being I had ever seen. Perched next to him on the couch, a gray, round woman smiled contentedly. A boy-man rocked in a ladder-back chair across from the pair. Permeating the air was the odor of rotting flesh.
>
> I introduced myself and explained why I had been sent to their home by the physician. Then George, Fernie and I discussed the recommendations for treating the oozing mass of raw tissue under George's overalls. George said he'd like the ulcers to stop hurting and heal up so he could get into his garden. We agreed that I would come every other day to clean and dress the ulcers. My next step was to introduce hygiene and diet as helpful in promoting ulcer healing and preventing of their recurrence. Hygiene sounded good on paper, but bathing meant heating water carried in from the pump. Diet changes meant lifestyle changes. Although informed of these methods which could lead to a higher level of wellness, George and Fernie did not choose them.

> The treatments were initially successful in helping the healing process. Gradually, however, George's legs began to deteriorate again. His strength waned. Rehospitalization strengthened him and reestablished the healing process. Home once more, George basked in the sun on his porch. But the ulcers wept again, too soon for the local hospital to readmit him under his SSI benefits. Thus, arrangements were made for admission to the State hospital. Two days later he signed out against medical advice. "The State hospital was too far away and I didn't know nobody and they were rough on me", were the reasons he gave. The local doctor, angered by George's "noncompliance" with the plan of care, refused to continue serving as his physician. That left me without a medical plan of treatment. Without that vital element, I was informed by my supervisor, I could no longer make physical care visits. And, since I had documented George's choices not to change his hygiene and dietary practices, he was ineligible for the Agency's health maintenance program. Other people in the community, I was told, could benefit more from the Agency's services.
>
> When I explained the circumstances to George, he told me that Fernie could "wash my legs and put that medicine on them." He told me that doctors never helped him anyway and he had no intention of ever going to one again. If his legs went bad again - "well, that was just the way things went." I left them the Agency's telephone number and assured them that a nurse could return to make an evaluation visit if they called for service in the future.
>
> Nearly a year had passed when Fernie called. She said that her husband had been in bed for nearly a month and was "awful sick." The Agency policy allowed a one-time evaluation visit, so I made the call. I found George's legs alive with the larvae of summer flies attracted to the steamy bedroom. I assured George that he would not be turned away from the hospital, even though he had no doctor. I called the ambulance and hospital, and prayed.
>
> One bilateral guillotine amputation later, performed in the emergency room, George was admitted to the hospital. Within four weeks, he was home again. Three months later he obtained prostheses and moved to another state where a brother lived.

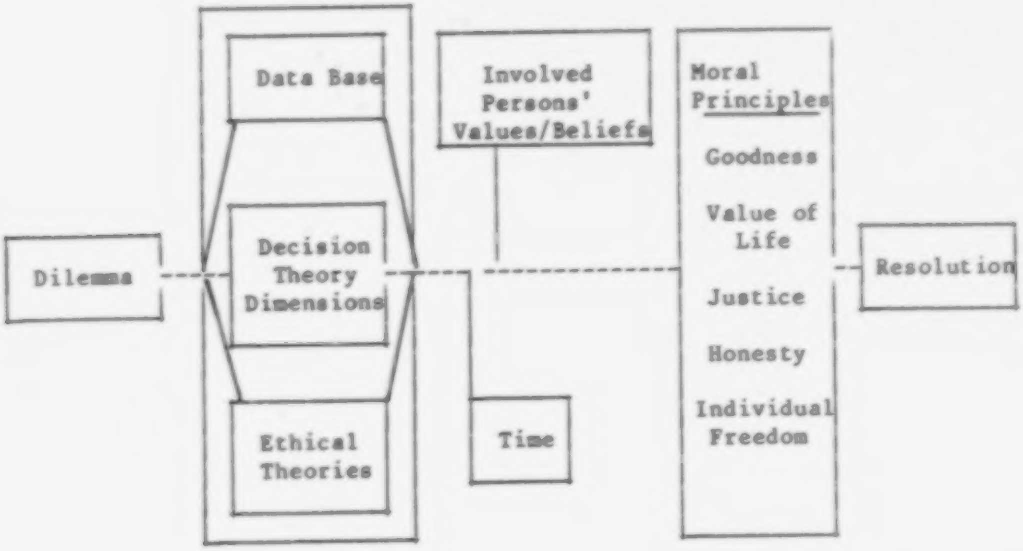
The questions remained, though. How had the situation come to this end? Had the system failed with George? Didn't George have the right to choose not to accept our health care? Didn't he have the right not to follow health education recommendations? Had I been wrong to discontinue my visits?

As I reflected upon the events of the past two years, I realized that I had faced two dilemmas, separate and yet intertwined. The first was the question of discontinuing the visits. George and I had the common goal of healing his leg ulcers. George had received information about care of his legs, preventive measures he could take, and the probable consequences of not taking action. He had chosen not to follow the recommendations. Therefore, would discontinuing home visits have any effect on George's health status?

The second dilemma revolved around George's autonomy versus my potential paternalism. Did my obligation to George, the ill person, outweigh my obligation to George, the whole person? George had his own priorities. Did I have an obligation to help him to reset his priorities? Would "help" better be defined as "coercion"? If George were aware of the options and ramifications of each option, then his choice among those options was his alone to make. What I believed to be best for George and what, ultimately, George chose to do could be diametrically opposed. My choice was between a paternalistic and advocacy role. Either role would have direct bearing upon my continuing or discontinuing visits.

I needed a method for sorting through this dilemma - for reworking it in preparation for similar situations which were bound to arise. A combination of Aroskar's action steps (Aroskar, 1980), and Thiroux's moral principles (Thiroux, 1980), provide a model for dissecting these dilemmas and validating the resolution (See Figure 1.).

Figure 1. A model of Aroskar's action steps and Thiroux's moral principles.


Dilemma
Data Base
Decision Theory Dimensions
Ethical Theories
Involved Persons' Values/Beliefs
Time
Moral Principles
Goodness
Value of Life
Justice
Honesty
Individual Freedom
Resolution

This model represents an approach for clarifying and refining the dilemma. The Data Base provides the nurse with all available information about the situation. Further, it requires the nurse to consider the proposed action, its context and purpose. Alternative choices and probable implications are also explored. The nurse, at the point of Decision Theory Dimensions, must reflect on who should make the decision, what criteria should be used in choosing the action, what role the nurse must take, and to what degree the client must freely consent. Aroskar suggests that the effect on moral principles also be explored here. I believe this is better accomplished when outlining the moral principles.

Ethical theories provide a framework for making decisions. Since equally unsatisfactory choices are inherent in ethical decision making, theories which promote reflective thinking are essential.

Raw fact-finding, identification of "shoulds", and the sorting out of ethical theories establishes a foundation for dilemma resolution. The personal values and beliefs held by all participants in the dilemma also influence resolution. The client may believe that death is better than loss of function, while the health care professional values life over function. Identification and clarification of values/beliefs held by the involved persons are important in directing the decision-makers' focus.

Time significantly influences dilemma resolution. In the event that a dilemma requires immediate action, contemplative reflection is a luxury. Having time to evaluate data from various perspectives and to discuss or debate it with others can be beneficial to the decision making process.

All ethical dilemmas involve at least one moral principle. The principles discussed here are broad enough to be integrated into ethical theories regarding the moral treatment of human beings. For example, goodness entails three elements: 1) promoting goodness over badness; 2) causing no harm (badness); and 3) preventing harm (badness). Actions which are creative or allow others to become creative, resulting in a harmonious outcome, carry out the principle of goodness.

Life is a basic possession of all creatures. Although it is common to all, each experiences life uniquely. No life has been everlasting in its earthly form. The value of the life principle recognizes the finiteness of life. Thus, it does not emphasize quantity over quality.

Justice speaks to the distribution of the benefits and burdens inherent in society. It requires that each contribute proportionately according to his/her resources, and that each sacrifice in like manner.

Honesty is the basis for any mutual trust relationship. Because morality relies upon agreements, and agreements are invalid without truthfulness, honesty is essential.

Individual freedom is to be considered within the limits of the other four principles. It allows persons to determine the best way to carry out the other four principles by instilling flexibility into the system. Without individual freedom, there would be no choices and morality would be practiced exclusively as dictated by the existing system.

Applying this model to the presented dilemma, the data base would contain the following:

INVOLVED PERSONS

George
informed of methods of self care and chooses not to participate; accepts outside assistance at intervals

Nurse
provides direct care and relevant health education

Fernie (Wife)
interested in care, but without influence

Nurse Supervisor
interested in agency administration, responsible for allocation of limited health resources

Physician
refused to continue services

PROPOSED ACTION

Discontinue home visits

CONTEXT OF PROPOSED ACTION

George has maintained his independence by virtue of staying in his own home. He left the institutional setting, at one point, reflective of his struggle to remain in control of his life. George demonstrated self-determination which may be defined as the "ability to care for oneself" (Thompson and Thompson, 1981, p. 188), when he sensed sabotage by institutional policy and the health care personnel who demanded him to behave dependently. It could be deduced that George had taken responsibility by cooperating with the part of the plan of care which met his goals.

PURPOSE OF PROPOSED ACTION

At the time of the action, the purpose for discontinuing the visits was to comply with Agency policy.

I propose now that discontinuation of visits could be based upon George's autonomy and my role as advocate.

ALTERNATIVES AND CONSEQUENCES

To Discontinue Home Visits.
To discontinue services would mean that George would lose all contact with health care providers. George's condition could rapidly deteriorate -- but this had happened on two other occasions when a health care provider had been on the scene. If George could not rely on others, he might begin to take interest in his health and mount an independent self-care

regimen.

To Continue Home Visits

Conversely, if the visits were continued, would there be any health benefits? Continued visits would provide contact with a health care professional. It could prevent a health problem from progressing to an irreversible state. The nurse could reinforce healthful living principles. Might reinforcement be a way of coercing George into accepting the nurse's values? Might George finally integrate these principes into his lifestyle simply to please the nurse?

Decision theory dimensions produce further information for consideration:

WHO SHOULD DECIDE AND WHY

OPTIONS:

George should decide how he wants to live and how much health care he wants to accept and for what period of time because he is autonomous.

The nurse should decide since she is acting in George's best interest and has the knowledge base and technical expertise.

The Agency should decide because certain criteria are in place for the discontinuation of home visits and the nurse is an employee of the Agency.

WHAT CRITERIA ARE USED

George should be treated as an autonomous individual; or, George does not have the knowledge to make a truly informed decision.

The nurse should act as an advocate for the client; or, the nurse should emphasize, by whatever graphic means necessary, what the likely sequence of events may be in an effort to convince George to change his lifestyle.

The Agency has a responsibility to society to provide as much service as possible, as economically as possible; or, the Agency must provide whatever service society demands it to provide because society is footing the bill.

CONSENT

George, informed, chose not to consent to participate in the recommended health practices. Would coercion manifest behavior resulting in desired outcomes?

Ethical theories, while not solving the dilemma, do expand the justification for decisions and action beyond simple slogans and "thou shalts".

Approaching this dual dilemma from a teleological framework, the utilitarian would look for the greatest good for everyone in the situation. George chose not to follow through with the recommended self-care practices. Continued home visits were expensive to the Agency, and, therefore, to society. Little, if any, return could be realized on the investment of time, money and resources. The greatest good for the greatest number, therefore, would be to discontinue services.

George's ethical egoism, individually based, required that Fernie and I act in his self-interest. This self-interest revealed itself in a "cause me no discomfort" demand. George behaved in a universal ethical egoism mode by acting in what he perceived to be his own self-interest. He ate when and what he chose to eat; he provided himself with no form of hygiene; he allowed his leg ulcers to be treated by others at times he identified as convenient.

The approach of the deontologist, who operate intuitively, might be to reject the situation responding to an evidently hopeless situation - not because the future (which would be consequential) looked dim, but because the present situation was so ghastly: a man with at least 200 extra pounds, oozing, foul legs and no personal hygiene.

Divine rule would dictate that I "love my neighbor as myself". If I respond to that edict, I must treat him as I would myself. I am obliged to continue to care for the ulcers and monitor his health as vigorously as I do my own.

The categorical imperative might lead me to discontinue services. Agency policy dictates that at least one of two criteria must be met for services to continue: a physician must issue a medical plan of care and/or the individual must participate in the nursing or medical plan of care established. Since George no longer had a physician nor did he participate in the nursing plan of care, visits must be discontinued.

Further justification for discontinuing services might be found in Immanuel Kant's practical imperative. George should not use me to meet needs that he chooses not to meet himself; also, I cannot use George to meet my need to provide care.

The values and beliefs of the persons involved influence the actions taken. I believe that the nurse is obliged to act as an advocate for the client. I value the freedom of the individual to make decisions regarding his/her own care and life style. Client autonomy and nurse advocacy are values from which I operate.

Autonomy provides "at least a nonabsolute legal right (for the person) to seek health care during an illness and to accept or refuse the recommendations of health care providers" (Smith and Davis, 1980, p.

1466). By claiming this right and acting upon it, the individual declares his autonomy. Autonomy demands self-responsibility. The individual obtains information from which he draws conclusions and make decisions. The results of those decisions, for the autonomous individual, belong to that individual.

As an advocate, the nurse "shows concern for and takes action in behalf of another" (Donahue, 1978, p. 144). Advocacy nursing also includes "nurse participation with the patient in reaching decisions regarding the management of an illness" (Gadow, 1979. p. 83). Sally Gadow pleads for a nurse who "will help persons become clear about what they want to do, by helping them to discern and clarify their values in the situation and, on the basis of that self-examination, to reach decisions that express their reaffirmed, perhaps recreated, values" (Gadow, 1979, p. 82).

The following statements define interactions which occur as the nurse advocate promotes client autonomy.

1) The nurse advocate explores with the autonomous client his/her perceptions regarding the situation.

2) The nurse advocate supports client-selected goals.

3) The nurse advocate informs the autonomous client of options for action to meet client-selected goals.

4) The nurse advocate informs the autonomous client of the potential outcomes of the options.

5) The autonomous client chooses the action(s) which lead(s) to the established goals.

6) The nurse advocate supports the autonomous client's choices and assists, as appropriate, in goal achievement.

Exploration with George of his perceived needs would be necessary in performing the role of nurse advocate. It would be my obligation to clarify with George what he is feeling and what he wants. Helping him to express himself in his entirety would leave him with a decision which was truly self-determined, not merely a selection from among options presented in him by others.

Jacques Thiroux (Thiroux, 1980) has defined five moral principles which direct the exploration of the aspects of a dilemma and provide guidance for pursuing its resolution.

The Value of Life Principle

Not only must I hold reverence for life, I accept death. My reverence for life provides me with a direction in assisting in the exploration of another's perception of life. Albert Schweitzer shared a perspective on life as being continually opposed to the lives around it when he declared "I am life that wills to live in the midst of life that wills to live" (Schweitzer, 1965, p. 26). If I value life in this context, I strive only to support myself - an ethical egoist view. If I value all life, however, I behave toward George's life with acceptance, accommodation, and advocacy.

The Principle of Goodness

A primary principle for the advocate is goodness. Activation of the principle is found in Schweitzer's definition of goodness as a preservation and promotion of life and the assistance for life "to achieve its highest destiny" (Schweitzer, 1965, p. 26). I am required to act in such a manner that no harm is caused, no harm is present and that goodness prevails, as perceived by George, for whom I am promoting autonomy.

The Principle of Justice

Justice, the fairness in a situation, requires that equal treatment be allotted each participant according to each participant's resources. I view myself as "responsible in developing relationships with other human beings" (Donahue, 1978, p. 148), which can result in fair distribution of whatever is being distributed. I must strive to develop a relationship with George which will help him to understand and clarify his perception of goodness and/or badness. The objective will be to assure that George receives as equal treatment as others in similar situations; that he receives proportionately the same contribution of goodness and badness as others.

The Principle of Honesty

Truth telling is essential in a relationship. It promotes open communication. Meaningful communciation, which clarifies perceptions, can only develop when honesty is the cornerstone. There is a need for honesty, especially between individuals in the client role and health care providers. A lie places a person in a position where he can "no longer participate in choices concerning his health, including the choice of whether to be a patient in the first place" (Bok, 1978, p. 231). If I am to be an advocate, I must be honest in all of my interactions with George. Then he can be honest with himself and his autonomy is supported.

The Principle of Individual Freedom

Individual freedom recognizes the uniqueness and singularity of the individual. It establishes his/her independence to make choices about his/her destiny. This freedom provides an atmosphere for authentic behavior. This authenticity is a result of the individual's awareness of and agreement with the motivation behind the behavior. Its product is autonomy. The individual is not subject to the will of another. "He may do what another tells him, but not because he has been told to do it" (Payton, 1979, p. 23). In the advocate role, I am obliged to acknowledge George's freedom to make decisions about his life.

Use of the Aroskar/Thiroux model is a rigorous exercise resulting in detailed information about the dilemma. Its step-by-step logic guides the decision maker. The dilemma's resolution will still be a choice between equally unsatisfactory alternatives; however, reflection on the route to the decision will reveal careful consideration rather than intuitive response.

Armed with the data collected through use of the model, I can reflect on the situation and rework it. I can also recall this experience when faced with similar situations; using it to direct my actions proactively. Now I would act as a nurse advocate and promote George's autonomy.

If I were to act otherwise, I would be an instrument of the system. I would not be George's advocate and would not be recognized as autonomous. The situation and the prescribed medical regime would take precedence over George as a person. My actions would be in support of the prescribed medical regimen and the situation, not in support of Goerge. Then, when George did not choose to participate in certain aspects of the care, he would be labeled "noncompliant".

In the role of advocate, I would assist George to clarify goals by promoting discussion about and reaffirming his values as they relate to the situation. Options for action and potential consequences would be objectively presented. Should I be tempted to graphically relate the gruesome details which might result if George did not participate in recommended health practices while downplaying the discomfort of treatment? I would be leaving my advocacy role. Such a digression would move me into a paternalistic role with the potential for practicing coercion - a forcing of a decision based on my values (no matter how well-intentioned) rather than George's.

George, as an autonomous individual, would select behaviors concurrent with his perceived needs and established goals. George's choice not to participate in recommended health practices could not, then, be considered "noncompliance". For "noncompliance" suggests a choice which does not agree with some value. However, George would have chosen an action in concert with his own values and would be consenting with himself. Thus, the term "noncompliance" could not be the behavior identified.

The visits could, therefore, be discontinued: not because Agency policy demanded it; not because resources could better be allocated to more "deserving" people; not because my perception of George's needs went unconfirmed by him; but because an autonomous George had experienced himself uniquely and made his own choices and I, as advocate, had assisted him in that self experience and supported his choices.

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Moral Distress in Nursing Practice: Experience and Effect

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Background and Need

Whether or not they are aware of it, practicing nurses frequently engage in making ethical decisions in the course of their work. Because nurses deal with fundamental human events (such as birth, death, and suffering), they encounter the many ethical issues surrounding these sensitive areas. While they are rarely in a position to control the actions of others, they must decide what their own moral actions should be in a multitude of situations. And because of the special nature of the nurse-patient relationship, they must support and sustain patients who are facing hard moral choices. As patient advocates and as the continuously present caregivers, nurses must also support patients who are experiencing consequences of moral choices made for and about them by more powerful agents in the health-care delivery system.

Nurses clearly do suffer moral distress as defined by Jameton (1984). In various studies and surveys they report situational constraints that keep them from implementing their moral decisions; and they report uncomfortable feelings as a result of their compromised integrity. Because of their peculiar position in the health-care power structure, and because of their conflicting loyalties and responsibilities (to licensing bodies, employing institutions, physicians, other nurses, patients and families), nurses are expecially prone to suffer moral distress.

There are no data to directly connect the experience of moral distress to the quality of care nurses give, but the connection can be inferred and it is supported in the literature, for instance by Kramer (1974). While she did not actually test the effect of the reality shock on patient care, in discussing the general implications of her study, she said:

> Most assuredly the care [given by a nurse who is in the throes of moral outrage, rejection, disillusionment, hostility, and despair] will be different and less effective if it is agreed that the climate and milieu that surrounds the patient (the nurse being part of that climate) is instrumental to his health maintenance and recovery process...A nurse who is severely at conflict and unhappy will experience difficulty in effecting the climate and relationship with her client that is most conducive to his well-being. (p. 219).

Nursing holds the good of the patient as its most important value. Most nursing philosophies and most individual nurses claim this as the ultimate aim of their practice. From this perspective, anything that threatens the delivery of good patient care deserves investigation and elucidation. Moral distress is such a phenomenon.

Purpose

The general intent of this study was to generate substantive theory about the relationships between the moral aspect of nursing practice and quality of patient care. The specific purpose was to explore the phenomonon of moral distress as experienced by staff nurses working in hospitals. For this study, moral distress was defined as: the psychological disequilibrium and negative feeling-state experienced when a person makes a moral decision but does not follow through by performing the moral behavior indicated by that decision.

Method

This was a qualitative, theory-generating study from a phenomenological perspective. Twenty-four staff nurses in two counties in a metropolitan area were randomly selected and personally interviewed regarding their experiences with moral distress. These nurses had indicated on a preliminary questionnaire that they had experienced moral distress as defined in the study. The interviews transcribed to over 350 pages of typewritten data. Data analysis was approached from the phenomenological perspective of granting authenticity to lived experience. The "appearance" of the phenomenon of moral distress was searched for a more "real" referent, i.e., the principles implied by the subjects' reported experiences. Validity can be established if the findings are recognized to be true by those who have lived the experience (Oiler, 1982, p. 181).

The experience of moral distress was summarized in a moral distress "equation" (see Figure 1).

Figure 1. The Moral Distress Equation

Experience

Moral Situation	+	Moral Decision About Right Action	+	Perceived Inability to Act	=	Painful Feelings and Psychological Disequilibrium

Effect

Coping Behaviors	+	Frequency of Cases	=	Effect on Wholeness	=	Effect on Patient

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In addition, an experience which is similar in its effects on nurses, but in which the components of the process are quite different, was identified. This experience was termed "moral outrage" (see Figure 2). Moral outrage occurs when nurses experience psychological disequilibrium and negative feeling-states because someone else performs an action they believe is immoral, but they are powerless to intervene on the patient's behalf. In these cases nurses do not believe they, personally, have done anything wrong.

Figure 2. The Moral Outrage Equation

Experience

Moral Situation + Moral Decision--Belief that Others are Acting Immorally + Perceived Inability To Stop Them = Painful Feelings and Psychological Disequilibrium

Effect

Coping Behaviors + Frequency of cases = Effect on Wholeness = Effect on Patient Care

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The moral distress phenomenon was described in terms of its situational, cognitive, feelings, and action dimensions. As categories emerged, relationships beween them were noted, and a model of the moral distress experience was developed (see Figure 3). Data were presented and discussed concurrently in narrative form. In an effort to capture the quality of the phenomenon, a great deal of material from the interviews was presented, using the nurses' own words.

Presentation and Discussion of Data

Information about Subjects

Subjects ranged in age from 26-58 years. They had from 3 to 30 years of nursing experience. While all subjects had worked as staff nurses, only thirteen were still working in that capacity. The "typical" subject was a young adult female (age 26-39), with 5-15 years of nursing experience, who was moderately religious, working in a specialty area or no longer working as a staff nurse, and with her basic nursing preparation as her highest level of education. Interviewer's impression of the nurses was that they were sincere, thoughtful, credible, and aware of moral issues.

Categories

The categories that emerged were: 1) kinds of cases; 2) frequency of occurrence; 3) contextual constraints; 4) feelings; 5) effect of moral distress an nurses' wholeness; 6) effect of moral distress on patient care; and 7) coping behaviors.

1. Kinds of Cases - At least eleven types of patient-care situations were described in which moral distress was experienced. The

ones mentioned most often were: prolonging life (e.g. inability to obtain "No Code" orders; aggressive/heroic treatments on dying patients); performing unnecessary tests and treatments (especially on terminally ill patients); and situations involving lying to patients. Although cases involved a variety of moral issues, the ones most often mentioned were: harm to the patient (in the form of pain and suffering) and treating persons as objects (dehumanizing).

2. Frequency of Occurrence - Subjects perceived that moral distress occurred frequently in their practice--only three reported a frequency less often than once a week.

3. Contextual Constraints - All subjects were able to name several external and internal constraints to their moral actions. Those most mentioned were: physicians, the law and/or law-suits, nursing administration, and hospital administration and policies. Several subjects reported incidents in which sanctions were actually brought to bear on them for doing what they believed was right. Nurses viewed physicians as punitive and peers and nursing administration as non-supportive in moral situations.

> If I'd said to the doctor, "Why are you ordering these blood gases," he would probably have cussed me out.

Only 3 of the 24 subjects mentioned that they had been supported by nursing administration in a moral situation.

> ...you're told you have a certain amount of back-up...but I don't know how much I'd want to bank on that. I was aware I was pretty much sticking my neck out.

> ...when it came right down to it, I and this other nurse were standing there with egg on our faces...All of a sudden the very people who were so glad we wrote the incident report were saying, "It's not such a big deal. It's unfortunate, but this doctor has worked here for years, and he brings in lots of revenue."

It appears that a nurse's perception of the constraints is more important than whether the constraint is actually "real." Nurses seemed to fear severe, but unlikely, consequences (e.g. loss of license to practice) as much as they did the more likely, but less severe consequences (such as a phyisican's anger). More experienced and knowledgeable nurses were more aware of their rights within the system; had a more realistic perception of the likelihood and severity of possible consequences; were more able to manipulate the system; and were, therefore, more likely to implement their moral decisions and suffer fewer instances of moral distress.

4. Feelings - All subjects reported that moral distress produced a variety of strong, negative feelings--predominately, anger, frustration and guilt. Anger was common in Code Blue cases, and guilt and anger were common in cases of lying to patients. Eight nurses spontaneously reported

feelings of guilt. In response to specific questioning, seven nurses, reporting ten cases, said they had not felt guilt. Most of these were involved in Code Blue cases. In general, those who perceived the physician as "decision-maker" and the nurse as "order-follower" experienced less guilt than those with strong feelings of nursing autonomy.

5. Effect of Moral Distress on Nurses' Wholeness - Nearly all subjects believed that ongoing moral distress had been detrimental to their personal or professional wholeness and were able to name some specific ways in which this was so. For instance: "I didn't feel like I was a good person...I felt worthless...I didn't feel like I was any good."

6. Effect of Moral Distress on Patient Care - Although subjects reported that moral distress was damaging to their personal and professional wholeness, when asked about its effects on their ability to give patient care, they were about equally divided in perceiving their patient care as better, worse, or not affected. It is speculated that quality of care may have been affected more than nurses perceived because:

A. It was too threatening to their self-image (as "good nurse") to think of themselves as not giving good care.
B. They may have defined quality of care more in terms of physical care than in terms of total patient care.
C. They may have measured quality of care by the amount of effort they put into it, or on the strength of their feelings, rather than by patient outcomes or how much "self" they had left to give after the energy-depleting experiences of moral distress.
D. They may have failed to measure the care they actually gave against the care they might have been able to give if their wholeness had not been affected by the incidents of moral distress.

Reported patient-care behaviors tended to be either in terms of either avoiding or compensating patients, or in changes in the nurse's emotional state.

7. Coping Behaviors - Nurses tried to resolve painful feelings both consciously and unconsciously. Unconsciously, they focused on the immoral actions of others (see Figure 2), focused on powerful constraints preventing their moral actions, or became unable to perceive negative changes in their patient care. One of the most common, but unsuccessful, coping behaviors was avoidance of patients or of job situations. The most common successful coping behaviors were to deny responsibility for the situation or for their own immoral action, and/or to believe they were able to have some control and effect upon patient-care situations. Nurses who coped successfully tended to compensate their patients rather than avoid them.

The moral distress phenomenon is summarized in Figure 3 as the "Moral Distress Model," and relationships between categories are presented narratively in this section.

Nurses frequently encounter patient-care situations in which they are aware of moral issues and believe they are responsible for deciding their own actions. They make a decision as to the correct moral action to take in the case. Nurses' cognitive moral framework and their feelings of empathy and desire to help the patient influence the decision about which actions are moral. Their amount of experience and knowledge of available options affect the degree to which nurses can circumvent constraints and implement a moral decision. Perceived, as well as actual, contextual constraints prevent nurses from implementing their moral decisions. Inability to act morally produces negative feelings and psychological discomfort/disequilibrium. The strength of the feelings is influenced by the degree of identification with the patient, and by perception of the nursing role in terms of passive rule-following vs. active decision-making.

This disequilibrium may have both positive and negative effects on nurses' ability to give patient care in the immediate and long-term situations. Various coping behaviors are used to restore psychological equilibrium and wholeness. Some of these coping behaviors directly involve changes in patient care, such as avoiding patients. The more frequently nurses are exposed to moral distress, the less likely the coping behaviors are to be successful. When nurses cope successfully, they feel some control over situations and tend to compensate the patients who are affected by the case; wholeness is maintained and they stay in nursing and remain able to give good patient care. When coping behaviors are unsuccessful, nurses feel powerless and overwhelmed. They may avoid patients and their patient care may suffer in various ways. Their wholeness is damaged as self-esteem is lowered. At this point, a nurse will usually change jobs or leave nursing altogether. Some stay, with further damage to their self-esteem and wholeness, and perhaps with further loss of ability to give good patient care.

Implications

This study has implications for nursing service in terms of the amount of support nursing administrators give to nurses in moral situations, and in terms of the type of nurse they wish to retain at the bedside. Those nurses who are unable to cope with moral distress and who leave bedside nursing seem to be those who are most aware of, and sensitive to, moral issues, and who feel a strong sense of responsibility to patients and for their own actions. If the wish is to retain these nurses, they must be supported and helped to cope with their feelings.

There are implications for nursing educators in terms of the need to include nursing ethics in curriculums. Since nurse educators, like most other nurses, lack a strong background in nursing ethics, they should become knowledgeable in this area as a part of their professional development. Only then will they be able to make informed judgements about whether, and how, to teach nursing ethics in their schools.

More research is needed to better saturate the categories developed in this study, develop and test relationships between the categories, develop a model of moral outrage, and broaden the generalizability of the study.

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Use of Predictive Factors in Severe Head Injury: Ethical Considerations

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Increasing attention by both the public and the health care providers is being given to persons who suffer severe head injuries. Rosin (1978) stated that one of the legacies of modern medical technology is the patient who is rendered permanently unconscious by trauma to the brain and yet continues to survive. Articles, books, and television programs have publicized the case of Karen Ann Quinlan who remained unresponsive for years. While the cause of her coma was not from a head injury, similar issues arise in persons who remain unresponsive for years following severe head injuries. More recently the case of Police Sergeant David Mack of Minneapolis received media coverage. After many months in an intensive care unit, it was decided that the changes for Sergeant Mack to regain consciousness were very, very slim; he was transferred to a long term care facility. However, several months later nurses noted that Sergeant Mack seemed to be responding when they talked to him; neurological evaluation confirmed that his condition was improving.

These two cases are examples of dilemmas that face the families of severe head injured patients and those who provide care to these patients. Cranford (1984) described the dilemma in the following manner:

> In these early stages the certainty of the prognosis is not sufficient to support a decision to discontinue some or all of the support services or to not initiate them. As time passes and the degree of certainty about prognosis increases, the patient is becoming less respirator dependent and more medically stable. Thus, the patient is capable of prolonged survival with quite ordinary supportive care. (pp. 36-44)

He predicts an increase in the number of persons in the Persistent Vegetative State (PVS) because of the improvement in care.

This paper will discuss severe head injuries, tests used in trying to predict the eventual outcome of persons who have suffered severe head trauma, societal issues that have caused increased concern about this group of patients, and the role of the nursing staff in providing care to those who have suffered severe head injuries.

Severe Head Injuries

Each year over ten million Americans suffer head injuries of which 400,000 are classified as severe or major. Motor vehicle accidents account for the largest group of injuries, but sports, falls, and personal abuse also contribute sizeable numbers. Head injuries are classified into three categories based on scores on the Glasgow Coma Scale (Teasdale and Jennett, 1974): severe (3-8), moderate (9-12), and minor (13-15). While there are distinct problems associated with moderate and minor head injuries, only the severe injuries will be discussed.

The Glasgow Scales are used in discussing head injuries: the Coma Scale (Teasdale and Jennett, 1974) and Outcome Scale (Jennett and Bond,-1975). The Coma Scale is used for classifying the person's level of arousal. Three areas are assessed: eye opening, motor response, and verbal performance. Each is observed independently of the other parameters. Scores from each of the three areas are summed to give the overall coma score.om Thus even if a person is unable to communicate, a score can be obtained fr the other two parameters. The Glasgow Coma Scale does not include all of the elements included in a neurological check, but it is widely used as an expedient measure in assessing the person's level of consciousness (Table 1). Scores are used to predict the eventual outcome for head-injured patients.

Table 1

Glasgow Coma Scale

Eye Opening (E)	
Spontaneous	4
To speech	3
To pain	2
Nil	1
Motor Response (M)	
Obeys	6
Localizes	5
Withdraws	4
Abnormal flexion	3
Exensor response	2
Nil	1
Verbal Performance (V)	
Oriented	5
Confused conversation	4
Inappropriate words	3
Incomprehensible sounds	2
Nil	1

Note: The Comma Score is the sum of the scores for E+M+V, and ranges from 3(lowest) to 15 (highest).

The Glasgow Outcome Scale is used in classifying the eventual outcome status of the individual. Table 2 presents a description of the four categories specified in the Glasgow Outcome Scale. While the percentage of persons classified as "Poor Outcome" or "Persistent Vegetative State" (DVS) is relatively small (3 percent and 16 percent respectively, reported by Jennett and Teasdale, 1981), the demands for care that this group places on the health system, family, and society require that more attention be given to the persons who remain severely disabled after head trauma.

Table 2

Glasgow Outcome Scale

- Vegetative State
- Severe Disability (conscious but dependent)
- Moderate Disability (independent but disabled)
- Good Recovery

The persistent vegetative state (PVS) is an enigma raising questions concerning what constitutes human life. Essential components of the persistent vegetative state, according to Jennet and Plum (1972), are the absence of any adaptive response to external surroundings and no evidence of a functioning mind in terms of receiving, processing, or transmitting information in a person who experiences long periods of wakefulness. The lay public often confuses the persistent vegetative state with brain death. Table 3 distinguishes the two states. The two states are differentiated on the basis of the level of functioning in the brain. No cortical functioning is found in the persons in the persistent vegetative state while in the brain dead person there is no function at the level of the brain stem. Bricolo, Turazzi, Feriotti (1980) caution against classifying persons as being in the persistent vegetative state until after a year has elapsed because of the hopelessness that is conveyed through the use of this term.

Table 3

Comparison of Criteria for Brain Death and Persistent Vegetative State

Brain Death	Persistent Vegetative State
No brain stem function	No cortical function
no respiration	spontaneous respiration
no brain stem reflexes	some brain stem reflexes
Heart stops in days	May live months, years

The PVS has been likened to a limbo state; the person survives but is not capable of interacting with family and friends. Cranford (1984) likened this state to the end-stage of dementia; a person in PVS has no measurable IQ. However, because the patient may appear very normal physically, the family continues to hope that the patient will eventually "come out of the coma." Jennett (1976) found that staff caring for patients in PVS perceived that the state was worse than death.

In addition to patients in PVS, recent attention has also been given to patients classified as making a poor recovery. Persons in this category are completely dependent on others for their care. They are, however, able to communicate, at least to some extent, with others. Bricolo and colleagues (1980) stated:

> In the long run, most patients who have suffered a prolonged impairment of consciousness are severely handicapped individuals with major psychiatric and physical disablement, yet show at least a moderate degree of mental capacity. Such patients represent the heaviest burden on their families and on the community because they cannot be salvaged, and yet there is no justification for abandoning them. The problem is simpler for patients in a truly vegetative state; there are fewer of them, and the human and social implications of their cases are somewhat less cogent. (p. 629)

Because of the "burden" the PVS person places on society, family, care givers, and resources, research has been aimed at ways to differentiate early after the trauma has occurred, between those who are capable of making a good recovery from those who will make a poor recovery, remain in the persistent vegetative state, or die. This is a veritable paradox. The development of technology and methods for improving the survival of persons with severe head trauma has forced professionals and lay persons to look at new ethical concerns. The increasing cost of health care has been one of the chief factors prompting examination of this concern.

Predictions of Outcomes

Selected factors have been examined to determine if a relationship exists between initial assessment criteria and the patient's predicted outcome to determine as early as possible after the injury who should receive aggressive treatment. The goal is based on the assumption that those with a better prognosis deserves more aggressive treatment. Some of the factors that have been found to have a relationship to outcome are depth and length of coma, and type of head injury. In general, younger persons have a much better chance of making a good recovery; however, this is not true for infants and children under five who have a higher mortality rate. A significant decrease in chances for a good outcome occur after age of 45 (Jennett and Teasdale, 1981). According to Jennett, Teasdale, Braakman, et al, (1979), patients with a Glasgow Coma Scale score of seven or below during the first 24 hours following trauma have less than a 50 percent chance of making a good recovery. As would be expected, there is a definite relationship between the length of time a person is unresponsive and his/her eventual outcome. The presence of an intracerebral hematoma in persons under 20 increase the likelihood of a poor recovery. Increased intracranial pressure that cannot be reduced has a high correlation with death or with a poor prognosis. Variables found to have little relationship to the eventual outcome of the patient include cause of the injury, whether or not there was a skull fracture, the hemisphere involved, and presence of injury to other body systems (Jennett, Teasdale, Braakman, et al, 1979). Levati and colleagues (1982) reported that the most reliable predictive indicators of type of recovery were absence of brain-stem reflexes, neurological status, abnormal motor patterns, arterial hypotension, and presence of mass lesions. Cranford (1984) noted that the most critical determinants in prognosis were: underlying primary cause, duration of coma, duration of abnormal brainstem findings, and duration of loss of cortical functioning when the patient awakens. Impaired pupillary responses and eye movement have also been associated with a poor outcome.

More recently, various modalities have been employed in an attempt to improve the precision for predicting the eventual outcome of the patient. Two that currently have wide application are computerized axial tomography (CAT) and evoked potentials (EP). The CAT scan by itself was not found to be a good indicator of outcome (Braakman et al, 1980; Snoek et al, 1979). The scan reveals information on structural abnormalities, but these do not always relate to the patient's functional abilities. The more sophisticated methods of scanning may improve the prognostic ability of the test.

Evoked potentials, an electrical manifestation of the brain's response to an external stimulus, have been investigated to determine their contribution to predicting outcomes following head injury. Narayan and colleagues (1981) reported that multiple evoked potentials (auditory, visual, and somatosensory) could accurately predict outcomes 91 percent of the time. Others, such as Greenberg and colleagues (1981), found that EP successfully predicted outcomes one year following injury in 80 percent of the patients. When persons who died from other than neurological causes were eliminated from the sample, the multiple evoked potential predictive ability approached 100 percent accuracy.

Ethical, Economic, and Social Concerns

Clearly the value judgement as to whether death is preferable to survival in a vegetative or severely disabled condition must be recognized as an expression of personal ethic and must be openly discussed among those responsible for decision-making in the care of such patients. The prediction of outcome and the quality of life associated with this outcome are becoming more reliable but still must be made cautiously with the full awareness of limitations of the methods used (Powner, Pinkus, and Grenvik, 1981).

There is, however, reason for concern. By making the prediction of outcome known to care-givers including nurses, the outcome may itself be influenced by their interactions with the patient and the patient's family. If nurses know what the likely outcome will be, will they unconsciously provide less stimulation to the patient? An expectation of hope may have a significant impact on recovery; the energy communicated by way of hopeful attitudes may affect the eventual outcome of the patient. We recognize that the development of accurate methods for prediction are necessary, while at the same time urging caution in the use of predictive factors.

Physicians are also concerned about the use of these predictive measures because they lack complete certainty. Some physicians believe that every patient should be given the benefit of doubt regarding care. After reviewing a number of studies on the treatment of patient with severe head trauma, Miller (1984) concluded that aggressive anticipatory treatment did not result in a greater proportion of persons who made poor recovery or remained in a persistent vegetative state. He stated that anticipatory aggressive treatment is, therefore, justified on ethical and economic grounds, assuming that resources used to help the patient to reach the highest level of function are of cost-benefit to both the patient and society.

Much attention has been given to the allocation of health resources in light of the escalating cost of health care--now consuming almost 10 percent of the gross national product. Many health policy makers believe that we cannot afford to spend more on health care. Therefore, concerns have arisen about who should receive health care and on what basis these decisions should be made. In addition to the cost of long term care needed by persons with poor recovery or in the persistent vegetative state, initial costs for immediate care of head trauma patients has caused the health care community to re-examine their protocols for patients with head trauma to determine who should be treated aggressively. There are no easy answers. Further appraisal and careful and cautious review are required. Evans (1984) believed that society must come to grips with life and death issues and make some decisions regarding the allocation of resources.

A methodology has been proposed by Powner, Pinkus, and Grenvik (1981) to assist in making decisions regarding treatment in persons with severe head injury:

1. Clarify the existing problem by stating it in both medical and nonmedical terminology.

2. List all alternative courses of action.

3. State both immediate and long-range outcome values and consequences of all courses of action.

4. Rank values or consequences in a professional scale from most desirable to least desirable as perceived by the family.

5. Make a selection based on this analysis.

6. Insist that a choice be made.

7. Validate the choices in ethical and medical terms through consultation and discussion.

It is critically important that the family and other health professionals are involved together in this process. Nurses from both intensive care units and long-term care facilities also need to be involved in the formulation of policies regarding care of these patients. They bring the perspective of day-to-day care of the patient and the concerns of the family that few other care-givers can provide.

Humane treatment and alleviation of the burden on the family are concerns of the health care team. Carson Strong (1981) has observed that no legal obstacle exists to letting persons die who have no hope of being mentally competent. However, making this decision is extremely difficult for all involved. It is frequently the nurse who provides support to the family after they have made the decision--whether it be to discontinue aggressive treatment or to continue it. Nurses have to be aware of their own feelings and convictions so that these do not interfere with this aspect of care.

The financial and emotional cost of caring for those who are severly disabled following head trauma is enormous for both the staff and family. The cost of care for Sergeant Mack was $224,000 for ten months (Cranford, 1984). Long term care is also expensive and can exceed $150,000 a year. Direct and indirect costs due to head injuries are estimated to exceed 2.5 billion dollars a year (Giannotta et al, 1984).

This is an area that requires scrutiny and attention. Many facets need to be included in the decision process. Will we rely solely on predictive factors to arrive at a decisions on who should get care? Who makes this ultimate decision? Bricolo (1980), a neurosurgeon, is concerned that society will come to lack compassion and concern for those who are dependent on others when care choices are forced on the basis of predicted outcomes. Although answers of today may be inadequate, there is hope that through discussions involving all health professionals, appropriate humane conclusions can be reached.

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When the "No Code" becomes an early death certificate: A case study from the family perspective

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The integrity of nursing as an art, a science, and a profession will be measured in the future by how effectively we met the care challenges of the 1980's. As society has awakened to the fact that providing health restoration at any cost depletes resources available for other concerns, we have experienced an increase in regulation and seen more importance placed on promotion of health. However, the care of the sick continues to be a basic responsibility for health care providers (ANA, 1980). Sophisticated technical abilities allow us to prolong life for the acutely ill and we are able to intervene more successfully during cardio-pulmonary arrest situations or at times of single or multiple organ failure.

Our magnificent array of technology and application skills have increased the complexity of health care options for consumers and providers. Intensive care units (ICU) can now give hope to those whose condition might have been incompatable with life even a few years ago. That ray of hope may, however, be very costly.

Determining who may or may not receive intensive care is one of the bioethical issues confronting society today. The traditional concepts for determining recipients of ICU services are being challenged by changing health care philosophies; by changing social attitudes; and by changing population characteristics. Several authors indicate that current demographics of intensive care consumers may conflict with mission and philosophy statements developed in the past (Jackson, 1984; Thibault, Mulley, Barnett, Goldstein, Reder, Sherman, & Skinner, 1980). Older and more acutely ill patients with narrow margins for survival are being placed in intensive care units. Of 117 patients who died in a one-year mortality study of 158 acutely ill ICU patients, 61.5 percent were aged 70 or over (Jackson, 1984). Thibault et al (1980) studied three ICUs with a total of 2,693 patients over a two year period and found that 32 percent of the patients were over 70 years of age. These findings seem consistent with the current increase in the number of persons over age 65. The oldest and frailest segment of our population, individuals age 75 years and older, is projected to increase by 50 percent for those 75-84 years and by 80 percent for those 85 years and over by the year 2000 (Brotman, 1981). It seems imperative that we look at what is occuring in ICUs now, before the health care issues of an increasingly aged society escalate further.

Already, general public media are addressing living wills and euthanasia as issues related to the availability of highly technical life-sustaining methods (Bowser, 1985). In a recent nursing ethics survey by the Minnesota Nurses Assocation, one of the five most commonly confronted problems identified by the 200 nurses responding was the code/no code issue. The question of resuscitation was viewed as a "specific aspect of the question of treatment and who will be treated" (Pearson, 1985, p. 101). The dilemma of when to provide and when to withhold care for the acutely ill elderly is heightened through delegation of scarce resource allocation decisions to the nurse at the bedside. The purpose of this study is to describe the consequences that ensued when an order prohibiting cardio-pulmonary resuscitative measures as a care option was invoked for a 77 year old male in a mid-western cardio-vascular intensive care unit.

Methodology

This is a combined retrospective and prospective case study. It is a very personal study because the patient was a relative of the author. The author's interaction with the situation began several days after the initiation of the "no code" order. Unstructured personal interviews included the family's thoughts on care prior to, as well as after the "no code" order and personal observation of health care provided to the client over a ten day period. While the longstanding relationship as a family member may lead to some bias on the author's part, it can also be argued that the depth of feelings revealed might not have occurred with a non-family member.

Subject

The patient on whom this case study is centered was a 77 year old male in a Cardiovascular ICU (CV-ICU). Medical background includes a coronary artery bypass (CAB) 12 years earlier. At the time of this study, a second CAB had been performed following an infarct from which the patient was not expected to recover. The patient had rallied, tolerated the surgery surprisingly well for his condition, and was transferred to an intermediate care unit.

Twelve hours post transfer, the patient was being assisted to ambulate when it was surmised that he aspirated and proceeded into full cardiopulmonary arrest. He was returned to CV-ICU in a fragile condition and there was supported with MA-1 ventilation and vasopressors. Though his hold on life was extremely precarious, the patient was able to communicate to his wife and physician that he was frustrated with his condition and would like the ventilator removed. While neither the family nor the physician were willing to stop the assisted ventilation, they determined that the client would not be forced to endure another resuscitative episode if his heart did stop. Positive, though not extreme medical, nursing, and general supportive health care services were to continue.

The family was aware that the final outcome was tenuous. To this family a "no code" was not synonymous with "no care" or "no hope". To them "no code" meant: Put up a good fight, but if the heart fails - do not resuscitate; that is, no electroshock and no cardiopulmonary resuscitation are to be provided. If the kidneys fail, minimum medical treatments are warranted, but no invasive therapy; that is, no dialysis, no arterio-venous shunts, no arterio-venous fistulas. The family's goal was to provide the client with an optimal environment for survival. To them this meant continuation of current medical therapies and nursing care to support the client's physical and emotional states.

However, the family began to feel that their position on the "no code" was either not clear or not shared by the health care staff. It appeared to the family that many of the nursing and medical staff seemed to view the "no code" request as an early death certificate. While tubing to intravenous, gastric, and ventilatory support systems was adequately maintained, it was rare that a health care provider addressed the patient or explained procedures. It seemed that the technology had assumed more importance than the person.

The performance of only minimal physical skilled care by the majority of RNs, RTs, PTs, and MDs was seen as decreasing the client's already slim chance of survival. The family's efforts to gain improved care for their loved one was frustrated by the lack of continuity in staffing patterns. In the ten days that the author was present, no nurse on any shift was assigned to the patient for two consecutive days. Thus, even though a few nurses were receptive to family concerns regarding chronic pain, allergies, exercise, and the client's need for control, and placed these concerns in the care plan, the utilization of appropriate interventions was inconsistent. One day the patient might receive adequate pain control through movement, positioning, and medication interventions and the next day he would not. At one point, a nurse refused to reposition the patient, even though the care plan noted his chronic neck and shoulder pain secondary to wryneck syndrome.

The family felt helpless and impotent. The patient was the dominant personality in both his family of origin and his family of procreation. The family expected exquisite care would be provided for the head of the family, but perceived that less than ordinary care was given. Because care was delayed, as exemplified by the patient being allowed to lie in his own excrement unless the family became adamant about having him cleaned, the health care providers were viewed by the family as lacking respect for the patient as a human being.

The family became fearful of requesting care for the patient from the nurses. Family members observed expressions of rejection on nurses' faces when another family member had requested help for the patient. From such experiences the family became afraid that if they were viewed as interfering, the patient would be treated harshly. Yet, not asking for help would mean that the patient could experience pain or discomfort. The family believed that the nurses had "given up" on the patient and wished he would die and stop taking up valuable nursing time they could be devoting to someone with better chances of survival.

The family initially perceived the "no code" order as a way to acknowledge the patient's desire to limit the vigor of care; and should their loved one die, to do so with some dignity and integrity. They later feared that the "no code" order had placed the patient in a twilight zone of ambilvalent nursing care. The personal dilemma for this family was that the "no code" order had led to care that was not at the desired level. Yet, withdrawal of the "no code" was believed to be against the client's wishes, a disrespectful action that would most likely subject the client to resuscitative measures and pain he desperately wanted to avoid.

In this situation the family believed that the nursing staff had limited their care activities only to those ordered by doctors and routine nursing measures. As consumers of health care services, the family believed that the "ill member" was entitled to holistic nursing care that would tailor strategies to the individual. The family was convinced that the "no code" order was viewed as a pre-death certificate and that care was rationed on this basis. Supportive nursing strategies such as: promotion of circulation and muscle tone through exercise; promotion of skin integrity through positioning, massage, and hygiene measures; and mutual planning for care with patient and/or family, were minimal. The patient developed a decubitus, eroded nares, and stiff joints. One evening he became extremely diaphoretic--the room temperature was reduced but the patient was neither sponged nor given a dry gown.

The wife, daughter, and granddaughter were present the night the patient died in the CV-ICU. They were very grateful that a nurse had called them in time to share the last moments of his life. This one very positive action was not enough to rectify the situation. The grief experienced by this family has been intensified by the guilt they feel because they were not able to obtain the desired quality of nursing care for the patient.

Analysis

Typically case studies are used to convey the intensity of real-life subject matter. It is evident that the impact nursing had in relation to this patient and family was immense. The family saw the problem of less than desirable care as being related to the "no-code" order. In actuality that was probably only one component of the situation. The family's assessment of an ethical problem was based on their perception of the scope and role of nursing. It is questionable if the nurses involved in this case viewed the level of care as inadequate. In addition, the philosophy of the ICU as a "life-saving" arena may not have been conducive to providing care to a critically ill elderly patient with a small chance for survival. Distancing from the patient and family by providing only minimal care may also have been a self-protective mechanism for the nurses.

The level of nursing care should have been an ethical matter for the nurses as well as for the patient and family. Curtin (1982, p. 15) reminds us that: "It is not in the exciting and dramatic areas of health care that nurses are most likely to transgress the human rights of patients, clients, and their families." The significance of nursing treatment decisions in day-to-day contacts is not felt as acutely as is the ethical significance in crisis decisions. Preventing a decubitus in a debilitated and vulnerable patient is certainly not as dramatic (and to most nurses not as rewarding) as successfully reviving a stopped heart. In this case, basic comfort care was disregarded. It is doubtful that this was intentional. It most likely occurred because the nurses avoided or were not equipped for decision making at the deliberative level. Every shift and every day a different nurse carried out doctors' orders for their eight or twelve hour period. The staffing pattern may well have interfered with the high level of personal energy, the personal/professional responsibility and "sensitivity to the human rights and values of others" which Curtin (1982, p. 40) identifies as prerequisite to deliberative care decisions.

The nurses in this situation practiced a very limited nursing role. Practice within the full range of nursing responsibilities as identified by the definition of nursing as: "the diagnosis and treatment of human responses to actual or potential health problems" (ANA, 1980) did not occur. Maraldo (1985) notes that: "nursing is caring, nursing touches you, nursing is compassion." She adds these components are all too frequently lacking-- "if we don't shape up, we may be taking orders from the physician that say 'talk to the patient's family QID'."

It is difficult to determine whether the focus on dependent medical-oriented nursing fuctions was a result of practicing without a strong definition of nursing and a sound nursing theory base or if the limited level of care was a device to meet nurses' needs. Care of the extremely ill patient requires tremendous energy (Jackson, 1984.) "Illness, absenteeism, cynicism, loss of caring, psychic numbness, burnout, and turnover" are sequelae to the energy expenditure and stress experienced by ICU personnel (Jackson, p. 136.) The stress may well increase when treatment options for recipients of intensive care services are contained, as in this care, by orders not to resuscitate the patient. Refusal of a service skill higly prized by ICU personnel may have many indirect ramifications.

The age of the patient cannot be ignored in analysis of this situation. At the same time that this 77 year old man was struggling to survive, a teenager was in the same ICU with newly diagnosed massively involved lung cancer. The nurses all seemed to know that the teenager was a star athlete and headed for college. It is a sad commentary that no one was interested in similar information about the older patient. He was much respected in his community and until his hospitalization, had been a very productive member of community organizations.

There is no clear reason or answer to explain the perceived omission in nursing care. As with most cases involving humans and health, a myriad of factors intermingle to create the final outcome. In the analysis of this situation a number of possible contributing factors has been identified.

Conclusion

It should be stressed that this is a case study and cannot be considered representative of all "no code" situations or of all critically ill elderly in ICUs. It can be suggested, however, that studies of the care given to patients labeled "no code" are warranted. Verfication of the trend toward placing the very frail and elderly in ICUs would also be useful. Nurses must consciously employ a conceptual framework in making decisions to determine appropriate care emphases and allocation of resources. In this particular situation, independent nursing strategies might have been more skillfully utilized to effectively diagnose and treat the human response of the patient and family to his health problems.

ANA's Social Policy Statement clearly points out that a professional concern to nursing is the extent to which society perceives nursing to serve society's interests. One major issue is the ability to afford health care while the predominant social value calls for general availability, accessibility, and acceptability of health care.

The extremely ill elderly, with limited chances of survival may become central figures in a dilemma between decreased care levels that would either lower costs to the population as a whole, or free resources to serve other groups versus expensive yet high quality care for this sub-group of very ill elderly people. Society will be watching nursing's response.

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Involuntary Hospitalization in a Residential Care Facility

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Dilemmas, Issues, and Conflicts

The residential care facility where I am Health Services Supervisor has a census of 194 residents, 98 of whom have a primary psychiatric diagnosis. Approximately 120 residents take psychotropic medications. One year ago, approximately 50 residents were on involuntary status, today only 24 residents remain on involuntary hospitalization. To be released from involuntary status requires special permission from our consulting psychiatrist or the resident's social worker. Even while on temporary leave from the facility, residents are encouraged to follow their treatment plan including medication regime. This setting is seen as conflictual to some people who do not understand how a person can be "committed" to an unlocked residential facility. Because of the design this residential facility, residents are seldom ordered to reside there unless they agree to come.

Ethical dilemmas may result when a resident experiences severe exacerbation of psychiatric illness, for instance, by becoming suicidal, homicidal, or acutely psychotic while refusing voluntary treatment on an in-patient basis. We must then examine the rights of the resident who is experiencing exacerbation of illness, in balance with the rights of the other residents, and the safety of our staff. Application for involuntary hospitalization is not made for staff convenience. Linn County Care Facility staff first assesses the mental status of the individual and determines whether or not he/she is dangerous to himself or to other residents and staff. Determination is also made of the person's type and degree of mental illness or mental disorders, and whether or not the individual has the judgment or insight to get the necessary treatment voluntarily. These three criteria must be met without violation of the resident rights, and are based in state laws (Iowa Code 229; Hospitalization of Mentally Ill Persons).

Recently John Monroe, Hospital Judicial Referee for Linn County and Gary Jarvis, Assistant County Attorney for Linn County clarified the process for involuntary hospitalization. John Monroe stated that there must be clear and convincing evidence that the person is: 1) suffering from a mental illness or mental disorder ; 2) physically dangerous to themself or others, and/or likely to create or inflict serious emotional injury on others as a result of the mental illness or mental disorder; and 3) would lack necessary judgment or insight to get treatment voluntarily. The application for involuntary hospitalization must be filed by someone with knowledge of that person's mental illness; and supporting or corroborating documentation must be provided by someone signing an affidavit. A letter from a doctor is necessary along with the applicant's signed statement. A judicial referee is assigned or appointed by the district court judge. In Linn County, Monroe was appointed. It is necessary that the person appointed be a practicing attorney in the county where he will act as judicial referee. Represented at each hearing is the respondent (potential patient), the applicant and signer of the affidavit, the psychiatrist performing the evaluation, the judicial referee, the county attorney or his designate, the attorney for the respondent, the Linn County Patient Advocate, and any other family or interested parties. Gary Jarvis has been with the county attorney's office for many years, the last five involving involuntary hospitalization hearings in which he represents the applicant. He informed me that family involvement is, at times, a problem as the patient seems to especially hostile towards family members who sign the involuntary hospital application, or are involved in a negative way with the hearing process. He believes that it may be beneficial for the family to be present for support of the respondent. Because of the type of residential facility that we have and the long term employment of our direct care staff, another ethical issue arises regarding the direct care staff and the signing of involuntary hospitalization applications. Many of the direct care staff are like family to the residents who have no other family. Our direct care staff work with the residents on a daily basis on the individual's unit. As a result, staff may bear the same hostility that is often shown to family members. Therefore it was decided by Linn County Care Facility management staff that direct care staff would not be involved with the involuntary hospitalization procedure. This is spelled out in our policy and procedure related to involuntary hospitalization which states that only designated staff members may be involved in involuntary hospitalization (see Exhibit). These are the staff who are in management positions and who do not have daily on-going contact with patients.

Jarvis has also noted that, in a residential setting, ethical problems can arise if a voluntary resident who is judged to be a danger to others wishes to leave against medical advice. Because of this, it is specified in the resident's rights and in our policy and procedure for involuntary hospitalization that an individual may be transferred to the Linn County Psychiatric Unit for 24 to 48 hours while the involuntary hospitalization application is pursued. There must be an immediate threat to self or others for this process to be used.

In an interview with Pat Kloppenstein, Patient Advocate for Linn County for the past eight years, she explained to me that her role is to provide professional advice after the individual is hospitalized on an involuntary basis. She helps them to understand what has happened, and what their rights are, including opportunity for appeal. The appeal must be made within five days of the initial hearing and takes place before a district court judge. Kloppenstein visits all individuals who are on involuntary hospitalization status in Linn County. I asked Kloppenstein if the resident's pride, self esteem, and sense of control are lost because of this process and she informed me that these are things that she talks with them about, helping them to understand the reasons for the involuntary hospitalization and pointing out that it is not done as punishment, but rather as a way to help the person receive the necessary treatment for the exacerbation of illness.

It is important for Linn County Care Facility staff to maintain a trusting relationship with the resident throughout this procedure and help the patient/resident regain a sense of control and self esteem. Throughout the procedure it is imperative that Care Facilty staff treat the resident with respect, honesty, and dignity. Kloppenstein agrees that direct care staff should probably not be involved in the involuntary hospitalization process and states that it may be best to have an overseer, or a person in a supervisory capacity, sign the involuntary hospitalization application.

Before involuntary hospitalization is begun we explain to the resident the difference between voluntary and involuntary hospitalization and encourage the person to go to the hospital or other facility for voluntary treatment. In our own facility this has proved to effective in maintaining the patient's sense of control and self esteem. More people make the decision for voluntary hospitalization than for involuntary hospitalization due to the explanation of the procedures, and the encouragement that they are capable of making a rational decision. This gives the resident a better feeling of involvement in treatment.

This choice is, of course, not always possible and involuntary hospitalization is sometimes the only alternative. The mental health advocate reviews the resident's length of commitment, and readiness discharge and makes recommendations in relation to each patient's record. Reports are filed by the facility every 30 days, 60 days, and then every six months by the consulting psychiatrist to the judicial referee of Linn County. At any of these dictated intervals the decision to drop the commitment can be made if the resident no longer meets the criteria for involuntary hospitalization. Any time an application for involuntary hospitalization is made, our social workers contact Kloppenstein and she is always present at the involuntary hospitalization hearing. This gives her a chance to familiarize herself with the case before she interviews. the resident on a one-to-one basis.

After application has been made for involuntary hospitalization and the judicial referee has ordered the respondent to be taken into custody, the Sheriff's Department is contacted to transport the resident to a locked psychiatric unit where the resident is housed until his hospital hearing takes place. This poses another ethical dilemma in that we wish to maintain the resident's self respect and dignity throughout this procedure. We do not want the person to feel like a criminal because he is transported to the hospital by the Sheriff's Department in a manner that would cause embarrassment. It is therefore our policy that the person be transported by our staff to the hospital. If it is not possible for our staff to transport the resident, we ask the Sheriff's Department to come in plain clothes, to stop at the front reception desk and call designated staff to bring the resident to the front office areas to meet the Sheriff's department staff. The resident is informed that the officers will be coming to transport him to the hospital. The resident is then walked to the front area accompanied by staff. Request is made by our staff that the officers use no means of restraint, for example, handcuffs. This allows the resident to make a decision on how he wishes to be transported and allows the resident the dignity of leaving the facility at his own volition. The only time officers are required to go to the unit and accompany the resident to the car is when the resident has completely lost control and is unable to make the decision to accompany staff to the front office. Family or significant others are contacted as soon as possible regarding the resident's change in mental status and the necessity for involuntary hospitalization application. Confidentiality regarding the resident's mental status and condition is maintained at all times.

In an interview with Roger Larson, Director of the Linn County Care Facility/Psychiatric Unit/Semi-Independent Living Unit, ethical concerns related to involuntary hospitalization application were identified. He stated "it is important that our staff be aware of potential ramifications and are fully aware of responsibilities involved in the involuntary hospitalization process." Mr. Larson emphasized the importance of direct care staff not being involved in the involuntary hospitalization application, stating that "after a person returns to the facility from involuntary hospitalization, it is sometimes difficult to relate to that person on a daily basis if staff have been involved in the involuntary hospitalization process. We wish to prevent any adverse staff reactions to that person." Mr. Larson is also concerned that "direct care staff may not know the ramifications and responsibilities of the committment process and that family members do not like to become involved because of repercussions from the patient. Mr. Larson also points out that the resident's rights, as contained in Chapter 57 of the State Code, include not only individual rights but also the rights of other residents in the facility to receive fair treatment without infringement on their rights. When asked why he felt the number of resident's on involuntary hospitalization status had been cut nearly in half in the last year,
Mr. Larson stated that he believes there are three reasons: 1) "the level of professionalism of management staff has definitely increased ; 2) services provided are such that we improve our abilities to deal with the clients which influences the clients' rate of success in being on their own, off committment status; and 3) consulting psychiatrists are willing to work with us on that overall effort to get people off the committment status if at all possible."

Mr. Larson expressed his feelings on informed consent as he stated the responsibility for informed consent lies with professional staff. I believe the process of ensuring that informed consent is provided has a lot to do with the level of professionalism of the staff. If staff are remiss in providing informed consent, the opportunity is not likely to occur, and information is not shared with the client. Capable and responsible professional information to the resident and/or guardian or family in this way helps responsible decision making to take place. A trusting relationship can be enhanced by honest and open information previous to and during the involuntary hospitalization procedure." Other residents that are aware of what is going on see the treatment of the individual in a fair and respectful manner and recognize that if the situation arose for them, they feel comfortable that they would be treated in the same manner. This provides a feeling of safety and reassurance.

When asked about our new policy and procedure, Mr. Larson stated "the only concern might be that the procedure outlined here, although it might sound good on paper, and may be good as far as how we go about implementing it, is still open to risk of abuse by professionals who may act in less than a professional manner, still claiming that they are following policy and procedure. For example, a staff person might influence a client in a certain way for convenience or expedience rather than basing the decisions on the situation and the person involved. When we follow this procedure, we must look at the best condition for the client, and safety of all residents and staff, not staff convenience.

Linn County Care Facility (LCCF) Policy and Procedure for Involuntary Psychiatric Hospitalization

SUBJECT: Involuntary Psychiatric Hospitalization of LCCF Residents

PURPOSE: To provide safety to the mentally ill resident who is a danger to himself or others; other residents and staff.

POLICY: When a care facility resident is determined to be of danger to himself or others, lacks insight regarding his/her care, and has impaired judgement that could cause harm to self or others, psychiatric hospitalization will be pursued. When the resident refuses voluntary admission, involuntary hospitalization and committment will be pursued by care facility staff.

RESPONSIBILITY:

Employee:	Action:
1. LCCF Staff	1. Contacts Health Services Supervisor (HSS), Program Manager, or social worker, or designated staff to relate information regarding any resident who is exhibiting signs or symptoms of homicidal or suicidal intent.
2. HHS, Program Manager, Social Worker, or designated staff	2. Assesses resident's mental status and lethability of resident, and provides counseling to resident.
	3. Contacts consulting psychiatrist and conveys assessment information and recommendations.
	4. Receives orders and recommendations of the consulting psychiatrist.
	5. Offers resident voluntary admission to the hospital.
	6. Pursues committment by contacting Clerk of Court (Monday - Friday, 8 am - 5 pm) or Judicial Referee with information regarding necessity for committment if resident refuses voluntary admission. NOTE: Weekends and holidays contact Judicial Referee on call.
	7. Transports residents to hospital emergency room for emergency hold.
	8. Contacts family or responsible person to notify them of transfer.
	9. Goes to Clerk or Court office and files involuntary hospitalization papers.

	10. Notifies Sheriff's Department and asks them to pick the resident up at the Facility or inform them that LCCF will transport.
11. HSS or designate	11. Calls psychiatric liaison at St. Luke's 369-7211, and gives information, including doctor assigned. NOTE: Community Mental Health Center doctor will be named by consulting psychiatrist to call and assume responsibility for the case.
12. LCCF Staff who signed committment papers	12. Attends committment hearing to testify regarding papers filed. Include any of the following information: is the resident suicidal; if yes, does he have a plan, history of suicidal attempts, history of mental illness; diagnosis of mental illness; alienation from significant others; age; sex; race; recent loss; physical illness; alcohol or drug abuse; isolation; seclusive behavior; unexplained changes in behaviors; depression; social factors; danger to self or others; aggressiveness; hostility; irritability; hallucinations; delusions; paranoia; specific statements or threats by the resident.
13. Social Worker	13. Completes counseling summary form and notice of emergency involuntary transfer; dischage form.
	14. Gives written notice of transfer/discharge to resident or responsible party prior to, or within, 48 hours of transfer/discharge.
	15. Places copies of counseling summary and notice of involuntary transfer/discharge in resident's social service file.

Effective Date ____________

Facility Director ____________

REVIEW DATES: ____________ ____________

____________ ____________

____________ ____________

INVOLUNTARY TRANSFER/DISCHARGE

Counseling Summary

Date:________________________ Transfer/Discharge Date:__________________________

Resident Name:____

Present at Meeting:____

____

____

Discussion Summary:____

____

____

____

____

____

Plan for transfer/discharge:____

____

____

____

A copy of this is given to the resident or responsible agent, and a copy filed in the resident's social service records.

____

Staff Date

141

LINN COUNTY CARE FACILITY

Notice of Emergency Involuntary Transfer/Discharge

Resident's Name:____________________________________Date:____________

Date of Transfer/Discharge:____

Reason for Transfer/Discharge:_____________________________________

____

____

"You have the right to appeal the facility's decision to transfer or discharge you on an emergency basis. If you think you should not have to leave this facility, you may request a hearing in writing or verbally with the Iowa State Department of Health within seven (7) days after receiving this notice. If you request a hearing, it will be held no later than fourteen (14) days after receipt of your request by the Department. You may be transferred or discharged before the hearing is held or before a final decision is rendered. If you win the hearing, you have the right to be transfered back into the facility. To request a hearing or receive further information, call the Department at (515) 281-4130 or you may write to the Department to the attention of: Chief, Division of Health Facilities, Iowa State Department of Health, Lucas State Office Building, Des Moines, Iowa 50319." This notice will be delivered to the resident or responsible party prior to or within forty-eight (48) hours following transfer or discharge.

____

Staff Signature Title Date:

cc: Resident or Responsible Party
Resident's Record
Department of Health
Physician
Sponsoring Agency
Commission on Aging Ombudsman

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